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ABSTRACT

This report highlights the progress of the 15 statewide family advocacy projects funded by the Center for Mental Health Services of the U.S. Substance Abuse and Mental Health Services Administration during the 1993 fiscal year. Section 1 provides an historical background and a summary of the interim report. A qualitative description of the progress of each project for the 1992-93 fiscal year is then provided for Georgia, Hawaii, Kansas, Minnesota, Mississippi, Montana, Nebraska, New Jersey, New Mexico, North Carolina, Pennsylvania, Texas, Vermont, Virginia, and Wisconsin. A summary of the collective experiences, barriers, and challenges of the 15 statewide family networks during this period is presented in section 3. Section 4 provides a quantitative assessment of the states' progress over the 3 project years on a selected number of variables chosen by the individual states. The major areas of advancement as well as the major challenges facing each of the statewide family networks are discussed in section 5. These include the need to reach out to underserved populations, to develop resources, to provide family support, to change the system of care, and to develop the infrastructure. An appendix presents details of the quantitative results. (DB)

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THE DRIVING FORCE:
The Influence of Statewide Family Networks On Family Support And Systems of Care

Statewide Family Advocacy Organization Demonstration Project
10/90 - 9/93
Final Report

Research and Training Center on Family Support
and Children's Mental Health
Portland State University

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10/90 - 9/93
Final Report

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TABLE OF CONTENTS

EXECUTIVE SUMMARY 1

I. Background and Overview 3

II. Description of Statewide Projects 9

Georgia 11
Hawaii 17
Kansas 23
Minnesota 31
Mississippi 41
Montana 49
Nebraska 55
New Jersey 61
New Mexico 65
North Carolina 71
Pennsylvania 77
Texas 83
Vermont 89
Virginia 95
Wisconsin 101

III. Qualitative Analysis 107

IV. Quantitative Results 113

V. Future Directions and Conclusions 119

VI. References 127

APPENDIX 129

EXECUTIVE SUMMARY

This report highlights the progress of the fifteen statewide family advocacy projects funded by the Center for Mental Health Services during the 1993 federal fiscal year. It is divided into five sections. Section One provides an historical background and a summary of the interim report. As far back as Knitzer (1982), the development of the Families as Allies movement in the mid 1980s, and studies by Friesen (1989) at the Research and Training Center on Family Support and Children's Mental Health in Portland, parents have been a driving force in efforts to improve service delivery. However, parents who were not organized into networks were difficult to identify, inform, or engage in family support or system change efforts. Consequently, the National Institute on Disability and Rehabilitation Research and the National Institute of Mental Health jointly funded the development of three separate cohorts of statewide family advocacy networks between 1988 and 1993.

Lessons learned from the earlier development of statewide family networks are published in reports by Koroloff, Stuntzner-Gibson, and Friesen (1990) and Briggs, Koroloff, Richards, and Friesen (1993). A qualitative description of the progress of each of the fifteen statewide family projects for the 1992-1993 federal fiscal year is delineated in Section Two. In this section a number of strategies available to parents and professionals to use in building statewide family networks are given along with a case study description of each of the fifteen statewide family networks. Each of these case studies provides data on how statewide family networks provide information, support, and advocacy to families of children with serious emotional disorders. A summary of the collective experiences, barriers, and challenges of the fifteen statewide family networks between 1992 and 1993 is presented in Section Three.

Accompanying this descriptive analysis of the progress of the fifteen statewide family networks, Section Four is a quantitative assessment of their progress on a selected number of variables. This numerical description does not represent all of the data collected by the networks. Because statewide family networks were given the opportunity to select their own data elements and encouraged to choose those items that would be most useful to them, it was not possible to provide an aggregate analysis of all data elements chosen as evaluation indicators by networks.

Based on analysis of data collected from the fifteen projects, statewide family advocacy networks, through dedicated parent leadership, have made major advances during the three-year period. The major areas of advancement as well as the major challenges facing statewide family networks are discussed in Section Five.

SECTION I: BACKGROUND AND OVERVIEW

Background

Statewide family advocacy organizations are established to promote family support, to facilitate system change, and to develop self governing capacities. The organizations discussed in this report are governed by families of children with serious emotional disorders. The genesis of federal support of these organizational arrangements is preceded by a number of significant historical events and the convergence of many influences. As the Families as Allies conferences were held around the country in the mid 1980's, families of children with serious emotional disorders were struggling to organize. In states where support groups were available, this support was an important service to families. In states without support networks, there were increasing requests by families for assistance.

Research by Knitzer (1982) and studies conducted by Friesen (1989) at the Portland Research and Training Center on Family Support and Children's Mental Health established that parents were a driving force in efforts to improve service delivery. However, parents who were not organized into networks were difficult to identify, inform, or engage in family support or system change efforts. Consequently, the National Institute on Disability and Rehabilitation Research and the National Institute of Mental Health jointly allocated $100,000 to be awarded to states for the development of statewide family- controlled organizations. The Portland Research and Training Center served as the conduit for providing federal support to family members in developing statewide organizational arrangements. Thus, the Statewide Parent Demonstration Project began. Portland Research and Training Center project staff were responsible for providing technical assistance to the funded projects and evaluating their progress.

Since this beginning, there have been three separate cohorts of statewide family advocacy networks that have received federal funding. Cohort one was funded between October 1988 and September 1989 and included five family organizations. At this time the request for proposals was responded to by 47 statewide family networks in 38 states and the District of Columbia. Each of the five statewide projects selected received $20,000. Projects chosen were located in Hawaii, Virginia, Wisconsin, Montana, and Minnesota. Cohort two was funded between October 1989 and September 1990. Three additional statewide projects received $20,000 each for the year. Kentucky, Indiana, and New Jersey were states that received funding during this time.

Cohort three was funded between October 1990 and September 1993. Fifteen projects were selected for funding with funding coming directly from the Center for Mental Health Services (formerly the National Institute of Mental Health). Projects selected for funding were located in Georgia, Hawaii, Kansas, Minnesota, Mississippi, Montana, Nebraska, New Mexico, North Carolina, Pennsylvania, New Jersey, Texas, Virginia, Vermont, and Wisconsin. Each project received $30,000 per year for three years.

An interim report, *Statewide Family Advocacy Organizations: Advances in Support and System Reform* prepared by Briggs, Koroloff, Richards & Friesen (1993) documented the progress of the fifteen projects during the 1990-1992 federal fiscal years. This final report focuses primarily on the progress of those organizations during the 1992-1993 federal fiscal year.

Overview of the Final Report

The progress made by statewide family networks funded by the Center for Mental Health Services during fiscal year 1992 and 1993 is the focus of this report. The study of the development and enhancement of statewide family networks has brought about a rich, descriptive, longitudinal, and ethnographic knowledge base. This report presents a description and discussion of the creative approaches used by fifteen different networks. It examines their preliminary impact on family support and advocacy on behalf of families of children with serious emotional disorders. These networks are examined through single case and group data analysis procedures. The data used comes from the self-reported judgments and observations of family members who are facilitating the developmental experiences, achievements, and outcomes of statewide family networks.

This final report examines the progress of the fifteen statewide projects as they pursued eight project objectives (See Appendix). These objectives were used as guideposts to facilitate their structural and operational development. This report highlights the progress and responses of family members in five major sections: Section One includes an historical background and a summary of the interim report; Section Two offers a qualitative description of the progress of each of the fifteen statewide projects for the 1992-1993 federal fiscal year; Section Three delineates an aggregate analysis of qualitative information presented by the fifteen statewide projects using the eight project objectives as a framework; Section Four examines the quantitative data collected by fifteen projects over all three project years (1990-1993); and Section Five highlights future directions of the projects and conclusions.

Review of *Interim Report*

The development of statewide family organizations was examined in the interim report by Briggs, et al. (1993). The interim report covered two major federal goals: (1) to stimulate and support the development of model statewide parent entities (organizations) that have the capacity to provide technical assistance, information, support, and networking structures to family members within states; and (2) to evaluate the conceptualization, implementation, and outcomes of family organizations. This section provides an overview and summary of that earlier work.

Statewide family advocacy organizations are an important catalyst in the system reform efforts in children's mental health. They increase the support, information, and advocacy of families of children with serious emotional disorders, as well as increase family member participation in the promotion of an improved child mental health system of care. The recent growth and experiences of statewide family advocacy organizations have furthered our understanding of the contributions family members make to advances in family support and system change technologies. In particular, the fifteen funded statewide family advocacy organizations have made a number of significant contributions as articulated by Briggs, et al. (1993, p.1):

- Each statewide family organization has some formal mechanism to communicate with families and professionals seeking information and services;
- Each family organization has a resource library with printed media and visual aids that they lend to families and professional groups seeking materials to educate people about children's mental health. The importance of the resource library to the work of the organization varies by state;
- Each family organization provides support networks via individuals and groups as a primary service;
- Each family organization is involved in building and coordinating a network of parents, representing various regions, although some organizations do not yet have support services available statewide;
- Each family organization is engaged in legislative reform and education. These activities serve as building blocks in the design of a system of care;
- Each family organization has demonstrated a commitment in reaching out to culturally diverse groups. More work is needed, however, to address the barriers that limit these families' experiences in the children's mental health system;
- Each family organization is seeking better ways to develop an infrastructure that supports the achievement of its complex objectives; and,

- Many family organizations are closer to their goal of achieving an independent status.

As with all new endeavors, the development of statewide family advocacy networks has been met with a number of obstacles and issues. These formidable challenges were articulated by Briggs et al. (1993, p.3):

Parent Coordinator Responsibilities. The parent coordinator's position includes three compelling but often incompatible roles: (1) working with families; (2) working for system change; and (3) building organization capacity. Although these roles are not organizationally incompatible, they are difficult for any one person to do effectively and are difficult to fund on the limited budgets of a statewide family organization. Managing the complex and multiple tasks of the three roles requires additional funding to hire more staff and attract volunteers to assist with some of the tasks of the parent coordinator.

Family, Work, and Personal Issues of Parent Coordinators. Family, work, and personal issues have had considerable impact on parent coordinators' efforts to manage the host of statewide activities and responsibilities. Studies are needed to examine the combined effect of these multiple demands and environmental factors such as job satisfaction and stress. The data from such studies may provide direction and assistance toward enhancing both the personal and environmental circumstances of the parent coordinator role.

Lack of Resources. Family organizations are always short of volunteer assistance, financial assistance, and support in the development of grants and contracts. Parent coordinators would like to expand their capacities to include functions such as family support, legislative liaison, planning, service coordination, and policy-making. However, to include these functions as distinct departments in their organization requires staff and financial resources. While of the 15 organizations depend on in-kind contributions and cash flow assistance by sponsoring organizations in order to pay bills and cover payroll , not all sponsoring organizations provide this support. In one funded statewide project, the parent coordinator went without pay for almost three pay periods. She subsequently left the organization seeking a position with more benefits and stable funding. The lack of financial resources is not the only impediment to the development of family organizations. Structural barriers to their growth and development include the lack of training and staff to handle multiple demands and challenges.

Inadequate Children's Mental Health Services. There is no entitlement policy that protects the interests and needs of children with serious emotional disorders. Many children are inappropriately classified or misclassified and fail to receive services to address their conditions. Children with emotional disorders often require the services of many agencies simultaneously. Generally, however, no one person or agency acts to coordinate these services. This lack of a coordinated service devlivery system may result in children's receiving inadequate services or duplication of services. For many children with mental health needs there are not sufficient resources to address their particular disability. Consequently, they are forced to fit into existing services, go out of state, or go without services. Professional barriers and tradition has made it difficult to mobilize policy and enact legislation to subsidize families as service coordinators or paid caregivers in any capacity. Lack of mental health services for children is one of the major barriers faced by statewide family organizations.

Interorganizational Relationships. The relationships between family and sponsoring organizations produce additional challenges and problems for organizations when there is disagreement on purpose, direction, accountability, and autonomy-related issues. A few of the family organizations are pursuing independent, nonprofit, tax-exempt status but do not have the active support and encouragement of their sponsoring organization. These relationships need to be evaluated and carefully monitored to track progress and barriers. Focus groups composed of individuals from family organizations that have an organizational sponsor need to be conducted to examine what works well and what is not supportive of the family organization.

SECTION II: DESCRIPTION OF STATEWIDE PROJECTS

The goal of establishing a comprehensive mental health system for children and adolescents is comparable to the goal of establishing competent support and advocacy systems for families of children with serious emotional and behavioral disorders. There are a number of strategies available to parents and professionals to use in building statewide family networks. In this section, an account of the progress of each of the fifteen statewide organizations during the third project year (October 1992 through September 1993) is given. This section provides a preliminary database for the study of creative approaches to the enhancement and development of statewide family networks. Each of the case studies provides data on how statewide family networks provide support, information, and referral to families of children with serious emotional disorders; reach out and expand contacts with families of diverse ethnic and cultural backgrounds; and enhance the network of parent and professional organizations interested in children's mental health. The case studies also elaborate on the structure and operations of the statewide family network.

GEORGIA

Georgia Parent Support Network

Introduction

The Georgia Parent Support Network (GPSN) has been an independent, family controlled organization since 1989. In many ways it is an example of families as mental health consultants to federal, state, and local child mental health authorities. GPSN is governed by a board of directors that sets policies and assists in resource development. An advisory board is composed of experts in education, social work, law, business administration, medicine, and psychology. The board is culturally representative of the population of Georgia. GPSN has a very close relationship with the Department of Human Services. They provide financial and in-kind support to defray costs and expenses. Funds are provided by the Episcopal Church and through generous donations by civic leaders and small fund-raising events. Following is a summary of GPSN activities during the 1992-93 project year.

Objective 1: *A mechanism for providing inexpensive two-way communication with identified groups and others requesting services.*

Georgia Parent Support Network (GPSN) established a nationwide toll-free number in the first quarter of year one. The number is advertised in the GPSN newsletters and brochure. This toll-free line continued to work well in the third year, and messages left by families were responded to within 48 hours. The time to return calls increased because of the increasing volume of calls received.

A press release was developed and distributed throughout the state to advertise the number. Tipper Gore was the guest of the Mental Health Association of Georgia in June, and GPSN information was used in conjunction with some of the press surrounding her visit. An article was written to be ready for distribution to newspapers statewide in July 1993. A public service announcement was also developed to advertise the number and was mailed to minority radio stations and newspapers. A thirty-minute television program featuring the network aired throughout cnetral Georgia in March. The program provided their toll-free phone number.

Brochures were distributed at the State Mental Health Managers Conference at an Adoptive Parents meeting and at a conference for educators attended by 70 new educators. One-hundred sixty brochures were distributed at the State Child and Adolescent Conference, 70 at a depression benefit, 50 at a breakfast for African-American clergy, 500 at a luncheon for Tipper Gore, and 350 at a special education conference. Newsletters and brochures were distributed at Mental Health Day at the Capital and at the legislative breakfast. Mailings were made to members of the

Psychological Association of Georgia in an effort to reach new families. The Department of Education distributed information about the Network to special education programs.

Objective 2: *A strategy to identify and engage underserved populations such as families from diverse cultural and ethnic backgrounds.*

Public service announcements about GPSN were distributed to minority radio stations and newspapers in order to advertise the network to families with diverse cultural and ethnic backgrounds.

GPSN continued to work with minority leaders to establish an awareness of the Network. In February, 1993 GPSN met with teachers and social workers. In March the Network met with representatives of the Black Legislative Caucus and leaders of the Atlanta Public School System. These meetings produced valuable results. Three GSPN members served on the Transition Steering Committee; a culturally diverse group responsible for providing recommendations to legislators in the development of a state bill (H.B. 100) to restructure government.

GPSN continued to work with community mental health centers and regional hospitals to reach and serve families from diverse cultural and ethnic backgrounds. The Network presented at the Managers' Mental Health Conference in December. Network staff provided a Christmas party for 48 children in the Regional Hospital on December 23, 1993. This effort is building relationships with the hospital. The Network presented at the S.W. Regional Hospital to the child and adolescent staff, using culturally diverse presenters. A mini-grant proposal was written to hire a parent of color to work with a Regional Hospital and a Psycho-Educational Center, in an effort to sensitize staff to cultural differences that affect families of color who have a child with an emotional disorder.

Episcopal Charities granted GPSN a mini-grant to hire a parent of color to do outreach and education. Beginning July 1, 1993 a parent was hired for 10 hours a week to talk with parents, professionals, and business leaders in an effort to develop a greater awareness of GPSN and to determine how GPSN can best serve the African-American Community. During the fourth quarter, the parent employee represented GPSN at many events, including attending three all-day meetings. During the fourth quarter GPSN met with leaders of Fulton County to discuss changes that needed to take place in order for children's mental health services to be more culturally competent.

Objective 3: *A method to identify local parent/family controlled organizations, to foster network activities among these local organizations, and to obtain information on activities of these organizations.*

To accomplish this GPSN obtained and published a schedule of activities of other organizations, including Parent To Parent and Parents Educating Parents. This information was reported in the GPSN newsletter as it was received, and parents were urged to participate. The March newsletter featured Families Forever, a statewide support system for adoptive families; and an article about the organization Parent To Parent. Parents were asked to submit information on family-controlled organizations in their local areas, and this information was collected and distributed to members.

A speakers bureau was established during the first quarter with a total of fourteen volunteers to speak on a variety of subjects concerning mental illness and mental health in adolescents and children. In the second quarter, speakers presented to three educational groups, a state hospital, a legislative subcommittee, a parent support group, two staff meetings at mental health centers, a meeting of service providers from newly funded areas, and a Community Mental Health Center Advisory Committee meeting. Presentations were also made at Mental Health Day at the Capitol (a joint effort of all mental health advocacy groups), and at Legislative Day. Three speakers represented GPSN in the third quarter, and two did so in the fourth quarter.

Members were encouraged to join collaborative efforts between groups. Three members attended 120 hours of training given by the Development Disabilities Council. Seven members worked on the Legislative Breakfast for the Ad-Hoc Coalition of the Human Crisis. Three members regularly attended meetings at the Mental Health Service Coalition. Two members attended Parents Educating Parents' annual conference. Over seventy-five members of the Network attended Mental Health Day at the Capitol.

The Network presented at the Georgia Association for the Mentally Ill (GAMI) state convention, and at the Mental Health Association's state meeting.

Objective 4: *A system of referring family members to existing family groups or to individual family members in their geographic area and for directing parents to existing agencies with the ability to answer questions and make referrals within the service delivery system.*

GPSN was contacted by many different people in all regions of the state requesting help in starting parent support groups. During the second quarter two community mental health centers contacted the Network about supporting parent groups. One of these is in operation, while the other is still in the planning stage. Presentations were made to staff in Cobb County and Bibb County Mental Health Centers regarding assisting parents in starting a support group. The Cobb County group is scheduled to start in May of 1993. Network staff presented to 16 areas of the state that received new funding, stressing the importance of parent involvement and support. Two new groups were started in the fourth quarter.

A family member, who is a minority board member, attended the Federation of Families' meeting in Washington D.C. in December, as part of the goal of training additional parents to do one-on-one support. Cultural sensitivity training was provided to seven families in the third quarter. The conference provided a training opportunity for families in September.

Objective 5: *An implementation strategy to strengthen the network of parents and parent organizations by increasing formal and informal contacts among groups and individuals.*

One meeting of the Network for training and information sharing was held in each of the first three quarters of the year. The first meeting in December combined the meeting and a holiday party. The second quarter meeting was held in Atlanta in conjunction with Mental Health Day. Several different training and information sessions were held that day. The June meeting was held in conjunction with a luncheon for Tipper Gore. During the fourth quarter meetings were held in five different areas of the state. A conference was held on September 13-14, co-sponsored by GPSN, GAMI, the Mental Health Association of Georgia, and others. The conference was attended by many families and professionals.

Information about conferences and training opportunities are passed on to members through the newsletter or telephone tree. The network and the state supported a parent to attend the Federation meeting. Twelve families attended the Family Support Conference in September 1992.

GPSN provided scholarships for parents to attend conferences and trainings, including some offered through other organizations. These included one to the Georgia AMI workshop, three to a Mental Health Association of Georgia workshop on cultural transition, ten to teenagers to attend the Consumer Conference in the summer, and ten for families to attend Mental Health Day at the capitol.

Objective 6: *A clearly articulated approach to providing technical assistance and support to newly forming or ongoing parent support groups, including "state-of-the-art" information on services for emotional disorders in children and adolescents, and the range of community based service options required to meet their needs.*

Four support groups were attended by GPSN staff during the year for technical assistance and support. Resource support was also provided in the form of books given to support groups to establish a basic library on serious emotional or mental disorders in children. The speakers' bureau was established and available to parent support groups.

Training opportunities continued to be offered in all regions of the state. These are available in the form of conferences by Family Support, GAMI, the Mental Health Association of Georgia, Parent To Parent, and Parents Educating Parents. The membership of GPSN is notified of these opportunities and is invited to attend, and limited scholarships have been offered by the Network. Families received training at The

First Annual Mental Health Summit, Sept. 13-15, 1993 in Atlanta, which was co-sponsored by GPSN.

Objective 7: *Provide a system for ensuring timely provision of information on pending legislation, state planning processes, opportunity for providing public comment or public testimony at various administrative or legislative hearings relevant to improving services for children and adolescents with serious emotional disorders and their families.*

A quarterly newspaper was published, with legislative alerts and hearing notices mailed out as soon as they were received. The telephone tree was also used to disseminate legislative information when time was not available to mail information to members.

Three thousand cards were distributed in January for mailing to the Governor and legislators, urging support of the Department of Human Resources' number one priority--funding for children and adolescents with severe emotional disturbances. Funding was obtained for five geographic areas resulting in more than six million new dollars for community-based services for those with severe emotional disturbances. Legislation to restructure the service delivery system for human services to make them more family-centered was introduced and passed in one year. Network families were a crucial part of making this victory happen. Parents testified at hearings every week. The telephone tree was used daily for updates and to tell members what action was needed. The new delivery system will have two levels of boards, and the Network was listed in the legislation as a reference for county commissioners in choosing members for the boards. A transition team of fifteen people was established to oversee the implementation of the new system. Two of the transition team are Network board members.

A legislative breakfast was held on January 15, 1993. It was sponsored by the Georgia Parent Support Network and co-hosted by 82 other organizations. More than 350 families, advocates, and legislators attended. The breakfast was followed by a two-and-one-half hour training session on mental health issues, pending legislation and actions needed, with two members of the Network as featured speakers.

Objective 8: *Plan for the continuation and expansion of the Georgia Parent Support Network following the completion of the contracts.*

The executive director attended extensive training in board development offered to board members by the Federation of Families for Children's Mental Health. Two network board members attended training at the Non-Profit Center in November. Four books on board development were purchased and are now being reviewed.

Meetings continue to be scheduled quarterly. At the meeting held in December, new members of the Network board, who were not family members, were installed. The first non-family member is the Executive Director of the Mental Health Association of

Georgia. She brings with her extensive organizational skills and fund raising expertise. Under the new by-laws the Network Board is 51% families and 49% interested others.

The March meeting was held in February to coincide with Mental Health Day At the Capital because many families were in town. More than 75 members received training, and got to meet and talk with their legislators. The third quarter meeting was held in conjunction with the Tipper Gore luncheon. Fourth-quarter meetings were held in five different areas of the state. Additional fundraising has been undertaken with some success.

The Network applied for and received a $775 grant from the Developmental Disabilities Council. An additional application has been sent to the Children's Trust Fund of Georgia. Grants to the Department of Education for $167,000; to Development Disabilities for $60,000; and to the Episcopal Charities for $3,000 were submitted. The Department of Education grant was not funded; however, continued support by the National Institute of Mental Health was received. The Network was selected to execute a training contract with the state to provide sensitivity training to professionals working with children with severe emotional disturbances in each of the 16 newly funded areas. The Network received $1,250 to hire a parent of color to do community outreach to the African-American community. This position has been filled.

HAWAII

Hawaii Families As Allies

Background

Hawaii Families As Allies (HFAA) is the primary voice of families of children with serious emotional disorders at the state, municipal, and grassroots community levels, despite the fact there is a limited children's mental health system of care in the state. HFAA provides support to families in a variety of ways, including teaching families about their rights and available services. HFAA does an excellent job meeting with and organizing families at workshops and conferences as well as connecting individual parents with other families.

HFAA is governed by a parent-controlled advisory board with an experienced, capable core of 14 members. The day-to-day affairs of the organization are managed by Deborah Toth-Dennis, the Executive Director. HFAA has linkages with Special Parent Information Network (SPIN); Assisting with Appropriate Rights in Education (AWARE); Learning Disabilities Association of Hawaii (LDAH); the Autism Association of Hawaii; and a number of local and state publicly-sponsored task forces. HFAA recently received its tax exempt, non-profit status, although it still maintains its collaborative relationship with its fiscal agent, Mental Health Association of Hawaii. Following is a summary of Hawaii Families As Allies' activities for the third project year (1992-93).

Objective 1: *A mechanism for providing inexpensive two-way communication with identified groups and others requesting services.*

HFAA uses a number of activities to maintain inexpensive communication with parents and professionals. They continue to receive calls from parents and professionals requesting support, information, and referrals. Although the number of calls fluctuate from quarter to quarter, the amount of time spent per call has increased. Intense technical assistance and emotional support is required for families in Hawaii because appropriate services are generally not available, often pushing families into crisis. The average length of calls is approximately two hours for initial intake, and five to seven days of follow-up, averaging two to four hours per day. Individual assistance has been critical in helping families access services.

HFAA does not receive enough long distance calls to support the cost of an 800 number. Family members and support group leaders are encouraged to call collect, although many from the neighboring islands still seem hesitant to do so. The Mental Health Association in Hawaii continues to evaluate the need to install a toll-free telephone number which they have offered to share with HFAA.

Objective 2: *A strategy to identify and engage underserved populations such as families from diverse cultural and ethnic backgrounds.*

HFAA used conferences, workshops and training meetings as opportunities to reach families of children with serious emotional disorders. Project staff lead workshops and co-sponsored different workshops and plenary sessions at conferences. Arrangement for travel scholarships were provided to a number of families on the neighboring islands from diverse cultural and ethnic backgrounds who would otherwise not be able to attend the sessions.

On January 15, 1993, HFAA co-facilitated a post-Pacific Rim Conference Focus Session. Both parents and professionals met to discuss their views on current services and the concept of "full inclusion" for children and adolescents with emotional, mental, and behavioral disorders in Hawaii. Later in the month the executive director provided a training workshop for parent support leaders and other family members. This all-day Saturday workshop presented an overview of the Individuals With Disabilities Education Act (P.L. 101-476), and information regarding how to develop an Individualized Education Plan. HFAA also provided a second, all-day, Saturday training workshop on Supplemental Security Income. Both workshops included parents from diverse ethnic backgrounds from neighboring islands. These parents were given airfare and transportation to and from the airport.

Preceding the Statewide Wraparound Conference in August, Karl Dennis, Jody Lubrect, and Kathy Potter met with a small group of HFAA parents from diverse cultural and ethnic backgrounds to share examples of appropriate wraparound services and to discuss the lack of such services to families and their children in Hawaii. Deborah Toth-Dennis of HFAA and Dixie Jordon of PACER presented two breakout sessions to professionals at the Statewide Wraparound Conference. The sessions were titled "Individualized Service Provisions: The Family Perspective." Most of those attending the conference were service providers who work with families from diverse cultural and ethnic backgrounds from all islands. At least a third of those attending the conference sat in on these sessions.

Hawaii Families As Allies and the A.W.A.R.E. (Assisting With Appropriate Rights In Education) program co-sponsored seven support groups on Oahu and the neighboring islands. The families described their experiences and concerns on a number of critical issues regarding education, behavior, family needs, and the lack of services in their communities.

Objective 3: *A method to identify local parent/family controlled organizations, to foster network activities among these local organizations, and to obtain information on activities of these organizations.*

The director of HFAA met regularly with directors of other organizations, family members, and professionals throughout the year. These groups compromise the Child and Adolescent Mental Health Task Force. This group provides a regular forum for networking and exchange of information, and regular training sessions for parent support leaders and other parents. People attending the training have been asked to collect and share information on both public and private service providers in their community at future training sessions. A resource directory is scheduled to be compiled with information on local referrals and resources for distribution to parents and professionals.

HFAA has printed a brochure which describes its services. Distribution of brochures has grown from 791 during the first project year to 2,389 during the third project year. Brochures are often distributed to conference participants.

HFAA continues to collaborate with the A.W.A.R.E. Program, University Affiliated Programs, Special Parent Information Network (SPIN), Child and Adolescent Mental Health Division, Departments of Education and Health, Alliance for the Mentally Ill, Catholic Charities, Child and Family Services, and others to assist families with referrals for services and with support. Some of the collaborative energy has gone into co-sponsoring meetings and conferences such as the May SPIN conference. Parents and professionals at this conference represented each community in the state and made for a well-balanced discussion of needs. Over 400 brochures were distributed at this conference. Support groups are sponsored through the collaborative arrangement with A.W.A.R.E. mentioned above. The average number of active support groups during the third project year was 8.

Objective 4: *A system of referring family members to existing family groups or to individual family members in their geographic area and for directing parents to existing agencies with the ability to answer questions and make referrals within the service delivery system.*

HFAA's newsletter informs family members about support group meetings and parent contacts in their area. Parents and professionals are also invited to call the office in Honolulu for additional information and referrals. The newsletter publishes articles with information about activities for HFAA and other organizations for the upcoming quarter. Distribution of the newsletter has increased from 2,900 during the first project year to 3,500 during the third project year.

HFAA continues to provide technical assistance to parents and professionals with appropriate options that address their specific needs. The project director collects information from parents and professionals who call HFAA. This is used to update an ongoing referral and resource directory for each local area that is disseminated to others upon request. This directory serves as a simple guide for obtaining services through the Department of Education, local referral and resources. It is helpful to all families, but particularly those in rural areas. It also serves as an adjunct to the "Finding Help" guide published by the Mental Health Association of Hawaii. The combination of this guide and directory provides information on resources available statewide for persons with mental illness.

Many families are in crisis and receive few, if any, services. Many who receive services are not receiving appropriate services. Several families have been referred to Protection and Advocacy to join a class action suit filed in federal court against Governor John Waihee; Director of Health Dr. John Lewin; and Superintendent of Education Charles Toguchi. Four of the seven children and their families filing the suit are members of HFAA. Six organizational plantiffs, including HFAA have also agreed to join the suit.

Objective 5: *An implementation strategy to strengthen the network of parents and parent organizations by increasing formal and informal contacts among groups and individuals.*

HFAA has involved family members as planning and policy making consultants on workshops, conferences, support groups, task forces, legislative issues, referrals, and individual services. This effective strategy has enhanced and strengthened the leadership and networking capacities of parents and parent organizations. This approach has increased formal and informal contacts among groups and individuals.

Through the annual SPIN Conference which is co-sponsored by a number of organizations, HFAA's families were provided with ample opportunity to network. Sharing of strategies informally, in the halls, or over lunch, has proven to be very effective for the families served. Although the Statewide Wraparound Conference was supposed to include parents as well as professionals, there were few parents attending. HFAA was asked to attend the conference at the last minute and was able to include and extend support to some family members.

Objective 6: *A clearly articulated approach to providing technical assistance and support to newly forming or ongoing parent support groups, including "state-of-the-art" information on services for emotional disorders in children and adolescents, and the range of community based service options required to meet their needs.*

HFAA uses the annual SPIN Conference to provide training, information and to support leaders, volunteers, and professional contacts. This year's conference workshops placed emphasis on topics such as full inclusion; Individuals With Disabilities Education Act (P.L. 101-476); developing I.E.P.'s; information on different disorders, services available in the community and how to access them, how to build working relationships between parents and professionals; (P.L. 99-660); and developing a relationship with legislators. In addition, HFAA has provided 22 other workshops in collaboration with other organizations.

The executive director has been meeting with local parent and professionals about starting a number of local Families As Allies networks. These networks would collaborate with the local mental health, school, and neighborhood support persons. The nine service areas of the Division of Children's Mental Health have requested support in starting parent groups. The Exceptional Family Program for the Army invited the project director to facilitate a support group meeting and speak to their staff about HFAA and the services that might be available to their families. In general, support groups have not been as successful as staff would like, mostly because of the limited amount of HFAA staff time available for support and the limited number of parents who are willing or able to volunteer as leaders.

The executive director continues to sit on several committees and task forces which keeps her informed about services being provided in different communities. This information is shared with others contacting HFAA.

Objective 7: *A system for ensuring timely provision of information on pending legislation, state planning processes, opportunity for providing public comment or public testimony at various administrative or legislative hearings relevant to improving services for children and adolescents with serious emotional disorders and their families.*

HFAA works closely with the Mental Health Association of Hawaii regarding legislative issues and family responses to emerging policy changes. HFAA's director is a member of the Child and Adolescent Mental Health (CAMH) Task Force, which includes many action-oriented and concerned parents and professionals seeking policy initiatives and legislative support for more resources and better management of existing programs and services. The project director also participates in the Child and Adolescent Mental Health staff meetings. Her chief role has been to assist professionals in adopting a family-centered strategy in planning and implementing statewide systems of care in children's mental health.

HFAA disseminates legislative information through its newsletter and through the newsletter published by the Mental Health Association. The Mental Health Association also operates a telephone tree which is used to inform and expedite updates about the progress of pending legislation to parents and professionals. The project staff assist parents and professionals with preparing testimony which provides them with the opportunity to share their experiences and needs. HFAA and the MHA testified on the feasibility and appropriateness of creating a statewide system of community-based residential and non-residential services for children and adolescents with emotional disorders in Hawaii. The CAMH Task Force presented a bill and a resolution for an act to follow up on the recommendations put forth in their report.

The Hawaii Families As Allies project director participated in a state delegation of interagency representatives who attended a CASSP Technical Assistance Center Collaborative Interagency Finance Workshop in Phoenix, Arizona. The delegation included 15 individuals from Child and Adolescent Mental Health Division, the business community, Department of Human Services, Department of Education, Governors'

Council, Department of Health, Senate Ways and Means Committee, Catholic Services, Medicaid, Department of Social Services, and parents. Individual consultants assisted each state delegation. The delegation focused on a vision of Hawaii. Additional consultants were brought in who shared their experience and information about developing competent and well financed systems of care.

Objective 8: *A plan to expand and develop the network across the State to include: (a) ongoing Board development and leadership expansion, including regular meetings, evidence of study and decision-making structure such as subcommittees, management and oversight training. Board membership and Network Members must be comprised of no less than 51% family members of children or adolescents with serious emotional or mental disorders; and (b) strengthening of the financial and legal independence of Network Members, including a strategy for revenue development, and timelines and specific attention to organization's legal status. If Network Members including the contractor are not incorporated, a plan and a timeline to incorporate and obtain tax -exempt status within the period of the contract award; and (c) a description of the policies that address the privacy of personally identifiable data.*

The HFAA advisory board had three special meetings during the third project year, in addition to their regular quarterly meetings. Special meetings were used to redefine goals and objectives of the organization, edit the strategic plan which was completed in May 1993, and develop committees to assist in the transition to an incorporated entity. HFAA added five new members to the board. There are now 13 regular board members, ten of whom are parents of a child with a serious emotional disorder. One of the new board members comes from the local military base. She will assist the organization in reaching out to the needs of military families in Hawaii.

HFAA has obtained their 501(C) 3 tax exempt status. It is also anticipated that change in the organization's legal status will enable them to secure additional funding. Due to major budget cuts statewide, it has not been possible for MHA/H to share their exempt status to apply for funding for HFAA. Funding is extremely limited and competitive. MHA/H has found it necessary to look into all avenues to support their own budget.

HFAA worked with the Department of Health in responding to the Substance Abuse and Mental Health Services Administration (SAMHSA) request for proposals to implement a children's mental health initiative in the state. HFAA has also been working on an agreement with Dr. Neal Mazer, Chief of Child and Adolescent Mental Health Division, to provide partial funding of the project director's salary as an additional fiscal resource to the organization. Other positions for parents within the state system are also being requested.

KANSAS

Keys for Networking

Background

Keys for Networking ("Keys"), a private nonprofit corporation, was formed in 1988 following two years of organizational meetings. Following the Midwest Families As Allies Conference, twenty-six parents from four cities began to meet on a regular basis to provide input to the director of Children and Adolescent Services in the Division of Mental Health. These parents established the groundwork for a statewide parent organization.

Keys is governed by a twenty-two member board, compromised of fifty-one percent parents. Keys' staff includes a full-time executive director, a parent assistance coordinator, and an outreach coordinator. Most of Keys' staff have children with serious emotional disorders. Keys maintains an office in Topeka, Kansas across the street from the state capital. A satellite office has also been established in Wichita, Kansas and is staffed by a paid parent coordinator.

The original funding for Keys came from federal dollars through the Kansas Social and Rehabilitation Services Division of Mental Health and Retardation Services. A second year of funding was provided by the state mental health and by youth services. Keys has also received allocations from United Methodist Health Ministries and the Kansas State Department of Education. Following is a summary of Keys activities for the third project year (1992-93).

Objective 1: *A mechanism for providing inexpensive two-way communication with identified groups and others requesting services.*

Keys for Networking established an toll-free telephone line in late 1991. Establishment of this line, along with continued outreach efforts, has resulted in greater numbers of phone calls than the organization's initial projections. At the end of the third contract year, the project was averaging as many as 800 phone calls per month. The toll-free number has made assistance and support accessible to more families.. Keys has contact with families from 90% of the state's 105 counties. The staff have developed a mailing list of approximately 1200 families and 900 professionals.

The funding received from United Methodist Health Ministries has contributed to maintaining a Keys phone line in Hutchinson, a town in south-central Kansas. This funding has also allowed Keys to provide mini-grants to several support groups.

Objective 2: *A strategy to identify and engage underserved populations such as families from diverse cultural and ethnic backgrounds.*

Keys' staff have systematically contacted agencies and organizations throughout the state to reach underserved populations including rural families and urban minorities. Outreach efforts have included public service radio advertisements, and presentations to agency personnel and civic organizations. Keys has also developed brochures and quarterly newsletters, some of which have been published in Spanish. Staff have developed relationships with the Office of Indian Affairs and the Minority Engineering Program at Kansas State University. Relationships are still being developed with the Asian community in Kansas. Project staff continue to communicate with two families in an effort to serve the Korean communities.

Project staff are working with O'Dell Jones, a minority community leader who works with African-American youth with behavioral problems. His work may help Keys network with these families. Keys has also met with Billy McCray, an African-American Sedgwick county commissioner who has expressed his desire to work with Keys in reaching African-American families in Wichita. Keys' staff have also made initial contact with the Sedgwick Commission on Families and Children, in Wichita. This commission has targeted a large African-American neighborhood for the development of community-based services for families.

Keys for Networking is responsible for the state ombudsperson program which is funded by the Department of Education. The ombudsperson program works with school service centers, special education cooperatives, and through regional Social and Rehabilitation offices to increase minority parent participation on regional interagency councils across the state. This has resulted in an increase of Keys' contact with minority populations. Ways in which Keys identified persons from diverse cultural and ethnic backgrounds was through the responses received in employment searches for the state ombudsperson position, the Keys wraparound project coordinator position, and the Keys outreach coordinator position. Keys for Networking advertised for the positions statewide and received a minimum of 20 applicants for each.

Keys' staff have contacted four local churches in the Topeka capital area describing the organization and its function, and inviting Mexican-American and African-American families to attend local support groups. Keys' staff also met with Wichita NAACP leaders/parents who challenged the overuse of time-out rooms in behavior disorder classes. Staff have made a number of contacts in the Western Kansas area, including discussions with individuals of Asian and Latino.

Objective 3: *A method to identify local parent/family controlled organizations, to foster network activities among these local organizations, and to obtain information on activities of these organizations.*

The Keys' office is able to maintain consistent contact with the support groups and contacts across the state, either by phone and/or mailed updates. The project has established two new support groups, provided financial assistance to six support groups for newsletter publication, and provided meeting space and child care for parents attending the meetings. At the end of the project year Keys for Networking had 32 support groups and contact people throughout the state of Kansas.

During the third project year Keys added support group/contact people in the following western Kansas communities; Meade, Clay Center, Abilene and Oakley. In southeastern Kansas they added a contact person in Arma. In northeast Kansas they established a support group in Topeka's 501 school district. On August 25, 1993, a member of Parents of Forgotten Children (a Topeka support group) volunteered to set up a booth at the Washburn University cultural fair to disseminate information on Keys for Networking.

Keys For Networking works with the Kansas Alliance for the Mentally Ill (KAMI) in providing support to two of the local AMI groups in two towns in which Keys does not have support groups. The project also published the activities of KAMI and Families Together (a parent organization for families with children with disabilities) in their newsletter. Keys worked with the local group of parents of children with autism in Wichita and with the Children With Attention Deficit Disorder (CHADD) parent group in Johnson County. Keys' staff worked closely with CHADD; attending a seminar they sponsored on attention deficit hyperactivity disorder and sharing in a reception for the families in the Kansas City area in May 1993.

Keys For Networking worked collaboratively with Wyandot Mental Health Center staff on activities in recognition of Children's Emotional and Behavioral Disturbances Awareness Week that took place during the first week in May. Minority families were a significant part of these activities. Staff began laying the ground work to begin a support group in the inner city area of Kansas City through this work together. Meetings with a coalition of parents and professionals in the Kansas City area have been held twice a month in planning the awareness week activities.

In late June, Creasa Cisco Reed, Director of Keys in Wichita, presented a two day "Parent Empowerment Training" for parents as well as professionals working with Keys families. This included training about negotiation skills, chain of command, advocating, and utilizing community resources. The response was very favorable.

Staff are working with Families Together to offer basic IEP training and advocacy training. Keys continues working together with CHADD, Parents as Teachers, the newly formed county chapter of Federation of Families for Mental Health in Sedgwick County, The Kansas Autism Chapter, The Kansas Alliance for the Mentally Ill and The Kansas Mental Illness Awareness Council, a consumer run organization. Keys attempts to work with school districts throughout the state of Kansas.

Keys staff are also working with parents whose children are at the Topeka Youth Center, a juvenile corrections facility and are using these efforts as a model to develop a similar parent group at a second facility. Contact has been made with Atchison; the first meeting will be next quarter. A meeting is planned for parents, administrators and legislators. Keys staff have also worked with the Topeka State Hospital children's unit in an effort to start a support group for any family members of children in this facility.

Objective 4: *A system of referring family members to existing family groups or to individual family members in their geographic area and for directing parents to existing agencies with the ability to answer questions and make referrals within the service delivery system.*

Keys continues to receive referrals from other agencies as a result of community presentations and outreach efforts. Support group information and contacts are routinely published in the Keys newsletter and other materials. The project continues to maintain a current database of families and agencies which is easily accessible. This has been an important tool for getting families connected with each other and providers. Keys has worked collaboratively with other children-serving agencies and organizations who are also compiling directory information on resources. A parent advocacy manual containing system and resource information is distributed to each parent support group. Keys has also utilized social work interns from Washburn University who are available to help with evening follow up and support group contact.

Patrina Heptinstall and Georgia Platt, project staff, met and trained a group of foster and adoptive parents and Social Rehabilitative Services (SRS) social workers in the Dodge City area. This meeting laid the groundwork for forming a support group specifically for foster and adoptive parents. This effort coincides with Patrina's contact with another parent forming a support group in Dodge City. Patrina has also met with people in three other communities who are organizing support groups.

Objective 5: *An implementation strategy to strengthen the network of parents and parent organizations by increasing formal and informal contacts among groups and individuals.*

In 1992 Keys' staff coordinated the first statewide wraparound conference that brought together approximately 400 people for a training in the wraparound process. One hundred of the attendees were parents. Currently Keys' staff and parents across the state serve as liaisons with agencies developing wraparound services. Keys was also selected to develop an ombudsperson project on interagency collaboration for legislatively mandated regional councils.

Keys has provided stipends to support families' attendance at state conferences and regional meetings. Travel reimbursement is available for parents who attend training sponsored by Keys and other family controlled organizations.

Keys for Networking staff have worked extensively with Topeka State Hospital in presenting sensitivity training to all of their staff; from direct care providers, to yard and building maintenance workers. This has been a very successful way to provide outreach to families in the Topeka area. These activities have resulted in many referrals as well as better care for youth placed in this facility.

Washburn University special education students attended the "Parents of Forgotten Children" support group meetings in Topeka. The communication shared seemed to open many eyes for the education students as well as the parents. Further, a number of students from Kansas University at Lawrence have been working with Keys to start support groups in southeast Kansas counties. Keys' staff have received and shared information with these students regarding mental health issues in Kansas.

Objective 6: *A clearly articulated approach to providing technical assistance and support to newly forming or ongoing parent support groups, including "state-of-the-art" information on services for emotional disorders in children and adolescents, and the range of community based service options required to meet their needs.*

Keys' outreach coordinator is in contact with support group leaders at least bi-weekly. Keys' executive director sends notification of legislative alerts and updates to support group leaders and the board meetings are scheduled throughout the state for additional contact and networking with parents. Keys also coordinates an annual training for support group leaders and provides each leader with a parent manual and statewide directory information.

Staff provided technical assistance to four new support groups in Oakley, Abilene, Clay Center and Topeka. Staff traveled across the western part of Kansas during August 1993 and made contacts with parents and professional in 5 cities; Hays, Oakley, Garden City, Dodge City and Great Bend. Word about the organization has spread to other areas of western Kansas from professionals that had been contacted by Keys staff. In September 1993 staff held a statewide Support Group Leaders' Conference in Great Bend which included up-to-date IEP and advocacy training.

Staff have made a concerted effort to track services in communities across the state as a part of developing community directories. Each staff member shares the information he collects. Progress has been made in linking with Corporation for Change's computer database on children's services and agencies all across the state. In addition, staff have met with Rehabilitation Services staff who are implementing transition work programs across the state in conjunction with the Department of Education. The transition work process/program information is also included in the project newsletter.

The Keys' office houses a library of resources and information which is available to all support groups and families. Duplicate copies of many of the books and publications in the Keys' office resource library have been purchased for several of the outreach sites. Materials are updated as new resources are located and secured.

Keys' outreach coordinator position was vacant for a seven month period, during the third project year. The responsibilities of this position, during this time, were carried out by the parent assistance coordinator and the executive director. This was a less than satisfactory arrangement and coincided with a complete staff turnover at the organization. However, the stability within the support groups helped to maintain organizational continuity.

Objective 7: *A system for ensuring timely provision of information on pending legislation, state planning processes, opportunity for providing public comment or public testimony at various administrative or legislative hearings relevant to improving services for children and adolescents with serious emotional disorders and their families.*

Through a system of mailing legislative alerts and a telephone tree that connects board members and support group leaders, the parents of Keys are able to make timely input into proposed legislation and provide testimony on the needs of families. Keys' staff and parent volunteers have also written letters and met with legislators and law makers to give a voice and face to their children's needs. "Parents of Forgotten Children," the Topeka support group held a meeting and invited Governor Finney to attend. Governor Finney heard testimony from five members of the group about their struggles and how difficult it is to obtain services in the state of Kansas. Governor Finney responded to support group members' questions after the meeting.

Keys' staff have developed a legislative telephone tree that provides communication links to all board members, support group leaders, and parent contacts. It was activated three times during the legislative session. In addition, Keys works with Kansas AMI, the Community Mental Health Center's Association, and the Coalition for Children to provide information to legislators on mental health reform and community-based service needs for families and children. Information on contacting legislators was also provided through the newsletter. Keys for Networking arranged for parent testimony to be presented in person before the House Subcommittee on Appropriations and filed written testimony with the Senate Ways and Means Committee. Telegrams, letters and telephone calls to legislators were generated on funding mental health reform and community-based service. Keys presented a legislative training workshop for parents in Wichita during this legislative session.

The outreach coordinator parent assistant coordinator, and attended forums and provided literature, statistics and first hand experience to the public and various candidates prior to the planned forums. Keys has made name tags for the parents who testify so they can be quickly identified and noticed.

Objective 8: *A plan to expand and develop the network across the State to include: (a) ongoing Board development and leadership expansion, including regular meetings, evidence of study and decision making structure such as subcommittees, management and oversight training. Board membership and Network Members must be comprised of* *no less than 51% family members of children or adolescents with serious emotional or mental disorders; and (b) strengthening of the financial and legal independence of Network Members, including a strategy for revenue development, and timeliness and specific attention to organization's legal status. If Network Members including the contractor are not incorporated, a plan and a timeline to incorporate and obtain tax -exempt status within the period of the contract award; and c) a description of the policies that address the privacy of personally identifiable data.*

The Keys for Networking executive board of directors met regularly during 1992-93. One of their major tasks was hiring a new executive director. The board of directors also held a retreat in May. The retreat agenda included examining issues of effective leadership by revisiting Key's vision, mission, and goals. Board meetings were changed from quarterly to bi-monthly to increase members' opportunities for participating in ongoing education relating to board member responsibilities. The board was organized into subcommittees to address the expanding funding base, refining the structure of the support group network, and developing a decision-making process that is responsive to individual disagreement and conflict without undermining the direction of the overall organization. A portion of each meeting is set aside for board development.

In September 1992, the board of directors met over lunch with the support group leaders. It was a great time for board members to meet with and discuss the many things the support groups do throughout the year. Three of the support groups have their own independent status and nine have adopted a unique name.

During the 1992-93 project year, Keys received four new grants from the U.S. Department of Education, Kansas Department of Mental Health and Retardation Services, Pressley Ridge Center for Research and Public Policy, and the Sedgwick County, Kansas Mental Health Association.

Keys mailed a parent satisfaction survey to approximately 1,200 parents and received 201 responses in a collaborative effort with Topeka-area education professionals. The results of this survey have been provided to state mental health and education professionals so that they can be aware of parent needs in their program and service planning. Keys is also using these results as the basis for their activities and technical assistance to support groups. The survey was adapted with permission from a parent questionnaire developed by the Portland Research and Training Center.

Keys is also working with the public-private agency, Corporation for Change created by the Kansas Legislature to monitor the implementation of services to children and families and to develop statewide directories.

MINNESOTA

Pacer Center's EBD Project

Background

PACER (Parent Advocacy Coalition for Education Rights) Center began in 1976 as a coalition representing Minnesota advocacy organizations concerned with the education of children with disabilities. Since 1978 PACER has been receiving federal parent-training funds through the U.S. Department of Education. They have become one of the largest parent-centers in the country. PACER manages a number of projects serving children with disabilities and their parents. One of these projects is the Emotional and Behavioral Disturbances (EBD) Project.

In 1988 PACER received a one year grant from Portland State University to begin a statewide parent organization for families of children with serious emotional disabilities; the EBD Project. At the end of the grant year, it was apparent that the need for information and support to families was still great, and in 1990 PACER obtained funding from NIMH along with other funding sources to continue their statewide organization efforts.

PACER, a nonprofit corporation, is operated by a board of directors representing each of 19 consumer/disability groups, the majority of whom are parents of children with disabilities. The coordination of the EBD Project lies with a full-time project coordinator, Dixie Jordan. A full-time parent advocate had primary responsibility for staffing the EBD Advisory Committee and organizing and maintaining the support groups.

The EBD Project Advisory Committee was incorporated as the Minnesota Association for Children's Mental Health (MACMH), but continued to function as an advisory board to the EBD Project. In the 1992-93 project year they obtained tax exempt status and secured independent funding. Following is a summary of EBD Project activities for the third project year (1992-93).

Objective 1: *A mechanism for providing inexpensive two-way communication with identified groups and others requesting services.*

PACER maintains a toll-free telephone number for parents outside the Minneapolis/St. Paul metropolitan area. This number is published on all PACER materials and is distributed by the support group network as well as at all workshops and meetings. Over the course of the year, between 30-40% of calls to the EBD Project have been from outside the greater metropolitan area. With 50% of the state's population residing outside the metropolitan area the availability of the toll-free line is a crucial link to Project services for rural families.

Handling phone calls remains the most time-intensive activity of the project, with calls going to the PACER central office as well as to support network members that are publicized through the *Pacesetter* newsletter. More than 4,100 calls were received during the 1992-93 project year by PACER. By the end of the year the mailing list had expanded to over 7,400 names.

Objective 2: *A strategy to identify and engage underserved populations such as families from diverse cultural and ethnic backgrounds.*

Approximately one third of all callers to the EBD Project identified themselves as belonging to diverse racial and/or cultural backgrounds. Since PACER does not ask the race of callers, the actual number may be higher. Of the more than 250 conferences that staff attended with parents (hospital discharge, mental health planning, corrections, and educational) over three years, from June 1, 1990 to May 31, 1993, 160 or (63%) were with racially and culturally diverse family members. During the final year of the contract 70% of the 100 conferences attended were with racially and culturally diverse families.

Although there have never been a large number of minority families at regular workshops and trainings, when the workshop was designed for a specific minority group attendance has been quite high, suggesting culturally specific workshops and activities may be an effective way to reach culturally diverse families.

PACER Center has a multicultural project which provides assistance to African-American and Southeast Asian families. Nearly half the calls to this project have been from minority parents of children with behavioral and emotional concerns. Direct services to such families are being provided by PACER's Southeast Asian and African-American advocates. An Hispanic advocate will be added as funds are secured. The African-American advocate has organized an information and support group for African-American parents of children with attention deficit disorders.

The EBD Project continued its involvement in the African-American Forum which convened to address the overrepresentation of African-American youth in EBD programs. In April the forum held a statewide conference for more than 120 professionals and parents of children with emotional and behavioral disorders which focused on culturally sensitive assessment and interventions in school-based services. They are planning a series of forums to address the issue of overrepresentation.

A Native American Advocates forum was organized and met at the American Indian Center to develop a strategy for reaching more Indian parents with information about the availability of advocacy resources and support services. Indian children are disproportionately represented in mental health and educational services. During the third quarter a Native American parent support group was convened in Minneapolis, for parents of children with all disabilities. At their second meeting there were nine parents, two of whom have children with emotional or behavioral issues. Group meetings continued in the Fall 1993.

An Indian Social Work Aide training where the major presenter was a PACER EBD Project staff person was attended by 80 Social Work Aides from throughout Minnesota. The Social Work Aide program is a home and school liaison position to reduce dropout rates among native youth; consequently, a large percentage of the students these aides work with are either identified as Emotional Behaviorally Disordered (EBD) or at-risk of emotional disorders.

The Mental Health Association sponsors an annual Native American Mental Health state conference each May. This was attended by 70 mental health service providers and parents, and included for the first time information about children and youth. An EBD Project staff person was on the planning committee for the subsequent conference in May of 1993, which scheduled breakout sessions specifically to address children's issues.

The EBD Project Coordinator met regularly with the minority task force committee established by the state Mental Health Division of the Department of Human Services to make recommendations for insuring that children's mental health services are provided in a manner respectful of the needs of culturally diverse families. The decision to organize a state level task force arose from the concern that conventional mechanisms, such as inviting parents to meetings or support groups, or soliciting their comments on proposed rules, were not effective in encouraging non-majority parents to participate in planning services.

Objective 3: *A method to identify local parent/family controlled organizations, to foster network activities among these local organizations, and to obtain information on activities of these organizations.*

The EBD Project developed or assisted in the development of 18 new support groups for families of children with Emotionally Behaviorally Disordered over three years in various regions of the state. In fall, 1993, there were 14 active support groups in the parent network. There was turnover in the groups throughout the three years due to relocation of the facilitator.

In Minnesota, county local advisory committees which must include parents of children with mental or emotional disorders are mandated by Children's Mental Health legislation, but not always implemented as extensively as PACER and others would like. A two-day leadership training was developed for parents who were interested in using their skills to help others by serving on policy committees such as their local Children's Mental Health Advisory Councils, as resources for other parents in their communities, or as support group facilitators. Approximately 45 parents have attended the training in the past year to learn about the diverse systems serving children and about their role in influencing the development of a comprehensive mental health system. Most have maintained activity in their communities. Statewide, parents attended 153 local advisory committees on children's mental health issues, although not all of the parents serving on the LAC's are members of support groups or advocacy networks.

PACER has solicited information about other groups and organizations through the *Pacesetter's* mental health news page, through monthly contact with each support group facilitator, at organizational meetings throughout the state, at professional inservices, and through topical mailings which request the input of parents who serve as community resources. EBD Project staff try to expand the possibilities of support and information to families by referring parents to all available resources in their areas, including those groups (such as CHADD) whose primary mission is to serve families of children with other disabilities, but may also include families of children with emotional and behavioral disorders.

In October 1992 PACER held a parent conference for parents of children with all disabilities. Of the 121 in attendance, 23 were parents of children with emotional and behavioral disorders. The newly formed Minnesota Association for Children's Mental Health had the opportunity to recruit membership and to describe their future plans. PACER's staff addressed issues such as Minnesota's new Behavioral Intervention Rule (governing discipline of children with disabilities), Section 504 of the Rehabilitation Act, and the Americans with Disabilities Act, all of which are expected to influence service design and delivery for children with Emotional Behavior Disorder.

In April, PACER mailed a two page *Mental Health Update* that included both Federal and Minnesota news to 6,900 parents and professionals. The update contained information about the support group network, the statewide conference and about the grant awarded to the Minnesota Association for Children's Mental Health (MACMH) to expand services to the support group network. The *Pacesetter's* Children's Mental Health News page went out to approximately 47,000 individuals and organizations in June. In addition a specific mailing regarding the statewide Children's Mental Health conference was sent. MACMH has also produced one issue of a newsletter, which has been mailed to over 500 people.

On May 13-15, 1993 the Partnerships for Children's Mental Health State Conference was held for 350 persons. This conference was a coordinated effort between local CASSP initiatives, including the Department of Human Services; PACER's EBD Project; and the Minnesota Association for Children's Mental Health (MACMH). The Department of Human Services provided reimbursement to parents for travel, respite, registration fees, hotel, and meals. The PACER Center coordinated the registration and disbursement of funds for families, co-hosted a parent caucus with MACMH, and organized a hospitality suite for parents. Ninety-two parents from throughout Minnesota attended. Dixie Jordan from the EBD Project was one of the keynote presenters. A caucus of 50 parents met at the conference to develop a list of needs and ways to effect change, which were then submitted to the Department of Human Services and to individuals who expressed interest in receiving a copy. Parents served as co-facilitators and presenters at the conference which focused on the development of local systems of care.

Objective 4: *A system of referring family members to existing family groups or to individual family members in their geographic area and for directing parents to existing agencies with the ability to answer questions and make referrals within the service delivery system.*

The support groups and resource parents' names were publicized in all three issues of the *Pacesetter* newsletter which was mailed to 47,000 persons. One effect of this wide dissemination was that leaders were contacted by the Department of Human Services to attend and present at a statewide training for children's mental health case managers. The number of resource parents have ranged from nine to 30.

PACER has developed and maintains a statewide of available mental health, educational, and corrections services in Minnesota (the *Resource Directory of Services in Minnesota* and the *Guidebook for Parents of Children with EBD*). This resource list helps assist families into locating appropriate services, and serves as a primary information and referral resource for families who children have emotional and behavioral disorders. The EBD Project is well known to most agencies serving families through the dissemination of the *Pacesetter* newsletter and other PACER materials and workshops. The guidebook, which lists county mental health services and contacts, was reprinted in March. More than 2,000 copies have been disseminated since its publication in 1991. A copy of the guidebook was given to each participant of the Children's Mental Health Conference in May. Updated EBD Support Network lists are sent to parents and professionals on an ongoing basis.

On September 20, 1993 the Project presented a workshop in Cambridge, Minnesota, to which 19 parents and professionals attended. A new support group is planned for Cambridge. Although the workshops are not specifically designed for the purpose of organizing support groups, they do bring parents together from large geographic areas who are then encouraged to identify community resources for children and to get to know the other parents. Three groups in a large, rural northern Minnesota area are networking to better serve the parents who would otherwise be unsuppported. In April the EBD Project will organize a workshop in their area with a focus on developing networking strategies. Workshops, which are co-sponsored by support groups, provide publicity for the group.

Objective 5: *An implementation strategy to strengthen the network of parents and parent organizations by increasing formal and informal contacts among groups and individuals.*

At the end of the project year there were fourteen active support groups, with attendance ranging from four to twelve parents, although a greater number receive information from the support groups. One group has a mailing list of over 100 parents. Most of these groups focus on advocacy as well as providing support; engaging in activities such as testifying before their local county commissioners about the need for community-based services to families; meeting with county social workers; joining with their school district to host a 6 week training for parents and professionals on ADHD issues; and making radio appearances and writing articles for local newsletters. One group set up a meeting where 50 parents and 6 professionals presented their complaints to the school board about the programming in the city's Alternative Learning Center. Individuals in eight of the support groups are member on their local children's mental health advisory councils. Two of the facilitators are also on the state children's mental health subcommittee; an advisory body to the Governor and policy makers.

The Children's Mental Health Conference mentioned in Objective 3 was a major opportunity for networking among parents. Parents served as co-facilitators and presenters, and time was provided for parents to initiate, renew and strengthen formal and informal connections with one another, and, where appropriate, to develop and expand formal structures, such as a legislative telephone tree network.

Over the course of the year the EBD Project, in conjunction with PACER, held more than 20 workshops focussing on emotional and behavior disorders, which have been attended by more than 1200 people. Topics covered included understanding the new community-based mental health services; understanding the services available through special education; reviewing the new Department of Education rules; Section 504 of the Rehabilitation Act; information for parents of children with ADHD; basic educational rights; transition services; and early childhood services and mental health issues.

Three regional CASSP conferences were attended by 200 parents and professionals. The Statewide "Partnerships for Children's Mental Health" conference was held with 350 parents and professionals attending.

Objective 6: *A clearly articulated approach to providing technical assistance and support to newly forming or ongoing parent support groups, including "state-of-the-art" information on services for emotional disorders in children and adolescents, and the range of community based service options required to meet their needs.*

Technical assistance and support has been provided in a number of ways. The EBD Project staff sent monthly informational mailings on topics such as legislation and upcoming workshops to support group facilitators and community resource parents. Legislative information from other sources was included, along with new information about the state Children's Mental Health Division activities. Project staff telephoned support group facilitators monthly to offer support and to collect data on their activities. The number of contacts between support group facilitators and EBD Project staff ranged from 12 to 64 contacts per month. Calls varied dramatically, from a facilitator's need for troubleshooting and intensive personal support, to simple informational requests. An extensive manual for facilitators was sent to each new group facilitator when they joined the network.

Facilitators provided individual advocacy attended meetings with parents in outlying parts of the state, and facilitated groups. Facilitators placed and received 1,113 calls related to family support during the third project year. Many facilitators expressed their concerns about the frequency of calls to their homes, and have begun to refer more parents to PACER directly for questions and support. Technical assistance requests intensified during the last quarter due to increased demand for facilitators to serve as advocates for families. Other resources included active groups not specifically linked to the EBD Project's parent network because they may serve specific disabilities such as ADHD or Tourette's Syndrome, because they are facilitated by professionals, or are time limited. While not a formal part of the existing network of groups, the Project maintained connections to these groups and, where appropriate, refered parents to them.

Objective 7: *A system for ensuring timely provision of information on pending legislation, state planning processes, opportunity for providing public comment or public testimony at various administrative or legislative hearings relevant to improving services for children and adolescents with serious emotional disorders and their families.*

The two-page mental health update, published twice-yearly by the EBD Project was mailed to 6,000 persons in Minnesota concerned with children's mental health issues and legislation. Legislative alerts from the National Mental Health Association, PACER, and Family and Children's Services were routinely mailed to all persons in the support network and to other individuals who expressed interest, such as members of the Governor's Subcommittee on Children's Mental Health. The telephone tree network, comprised primarily of community resource parents and facilitators, was used to alert families to new developments in rules and laws that needed their attention.

Much staff time was spent providing training and guidance on Minnesota's new Behavioral Intervention Rule, which limited the use of timeout procedures, suspensions and physical restraint, and promoted positive interventions for managing behavioral problems.

EBD staff mailed or handed out information to the network of parents regarding current legislative issues, including on the proposed repeal of state special education rules, the proposed federal Department of Education definition for SED that was offered to the public for comment and the definition proposed by SAMHSA; and encouraged network members to share such information with other families. Legislative bulletins and alerts were mailed to 250 parents.

EBD support group members reported that on 248 occasions, parents from support networks attended policy meetings during the three year contract period. Support group members testified on legislative issues 195 times during these three years. For instance, during the first quarter of the 92-93 year, parents submitted written comments regarding pending legislation 26 times, and gave presentations at 10 meetings regarding legislative issues. During the second quarter, more than 100 families, among them a number of parents of children with EBD, testified before a Senate Education committee that had proposed elimination of substantial sections of the state's special education rules. Three parents also testified before the State Legislature on the Integrated Funding bill and Prepaid Medical Plans.

Other activities by EBD and MACMH staff and parents included reviewing the 99-660 mental health plans, offering comments on the development of services (The Minnesota Association for Children's Mental Health, the newly-organized parent group, also has several representatives on the 99-660 committees), serving on the State Children's Mental Health Subcommittee, and meeting with the Integrated Funding Task Force. The State Children's Mental Health Subcommittee is the state level body responsible for reviewing the children's section of the state mental health plan, and dealing with issues such as standards and care, family community support services, and rules governing treatment of persons in residential settings. The integrated Funding Task Force met to develop a bill to address the multiple system needs of children. Four network parents participated in this committee, which successfully introduced the bill during the last legislative session. As a result of its passage local service agencies may form a "collaborative" to fund services to high-needs children.

Objective 8: *A plan to expand and develop the network across the State to include: a) ongoing Board development and leadership expansion, including regular meetings, evidence of study and decision making structure such as subcommittees, management and oversight training. Board membership and Network Members must be comprised of no less than 51% family members of children or adolescents with serious emotional or mental disorders; b) strengthening of the financial and legal independence of Network Members, including a strategy for revenue development, and timelines and specific attention to organization's legal status. If Network Members including the contractor are not incorporated, a plan and a timeline to incorporate and obtain tax -exempt status within the period of the contract award; and c) a description of the policies that address the privacy of personally identifiable data.*

The advisory group to the EBD Project incorporated as the Minnesota Association for Children's Mental Health, obtained tax-exempt status, and secured independent funding in 1993 from the Department of Human Services to provide services to the existing support group network and to expand the number of groups. The Board has a formal structure, with four committees, and has hired a coordinator to carry out activities under their new grant. PACER served as the fiscal agent of the grant until the group became a tax-exempt entity, and continues to provide technical support related to strengthening and expanding the organization. MACMH recently applied to the national Federation of Families for Children's Mental Health to serve as a state chapter of that organization. This group of parents served as Advisory Board to the EBD Project.

The creation of the MACMH represented almost five years of development by the EBD Project and was strongly supported by the PACER center. One of PACER's co-directors met monthly with the president of MACMH to provide technical assistance and share materials and information. Two staff persons from the EBD Project provided technical assistance at each monthly board meeting, and by telephone as requested.

Several of the support groups obtained small amounts of money to sustain activities such as child care services. MACMH provided small scholarships ($100-200) to interested groups to sustain or expand their development. They informed existing support groups that they are taking applications to provide financial assistance to the groups for expenses related to their operation and expansion.

MISSISSIPPI

Mississippi Families as Allies

Background

Mississippi Families as Allies (MSFAA) is a statewide organization that is governed by an ethnically-diverse, parent-controlled board. Currently 39% of the board members are minority members. A number of the board members are involved in advocacy and family support and many are also professionals working in a variety of settings. MSFAA has developed training materials to use in educating families and professionals about the importance of collaboration and family support.

One of the founders of MSFAA, Tessie Bruinini Schweitzer, is the executive director. She has organized a cadre of supportive legislators, professionals and family volunteers whose chief responsibilites are to aid in the development of policies and legislation that will result in better services and support to children with serious emotional disorders. MSFAA has received financial support from the Hinds County Board of Supervisors as well as from private donors. Following is a summary of MSFAA activities for the third project year (1992-93).

Objective 1: *A mechanism for providing inexpensive two-way communication with identified groups and others requesting services.*

Mississippi Families as Allies (MSFAA) installed a toll-free line in December 1990. Current usage averages 50 calls a month. Newsletters, short informational bulletins, and brochures are distributed in large numbers at any activity in which MSFAA staff or board members are involved. This is the main method of publicizing the toll-free number. A flyer was sent to each person on the MSFAA mailing list announcing the location of the new office, and including basic information about MSFAA goals and objectives.

The executive director was involved in numerous presentations and trainings to diverse groups over the 1992-93 project year. Some of the audiences included Children's Case Managers from the fifteen Community Mental Health regions; the Mississippi National Association of Social Workers, Jackson chapter; the Teen Issues Network; the Gulfport Parents Network; and the Medger Evers Community Center. Topics covered issues such as parent/professional collaboration, special education issues, blended funding, and child development in children with serious emotional disorders

Objective 2: *A strategy to identify and engage underserved populations such as families from diverse cultural and ethnic backgrounds.*

From inception the board has been racially and culturally diverse with minority groups comprising approximately 39% of membership. This has enabled MSFAA to have credibility and successfully reach the minority community. MSFAA has strong relationships with Head Start and the Black Caucus. Its Network members are working one-on-one in small neighborhoods, both urban and rural, to provide emotional support, crisis management services and develop self-help projects.

One board member, involved with the Jackson Public School system, (primarily underserved populations) was appointed to develop and conduct sensitivity and parent/professional collaboration training for parents and teachers involved in services for children with special needs. Her appointment has resulted in a larger number of underserved families learning of MSFAA and being served. MSFAA and Jackson Public Schools will build on this initiative by offering another *Developing Families as Allies* training program this winter. This will include money for transportation, free refreshments and materials, and free childcare for this event. MFSAA provides this type of financial assistance for all MSFAA sponsored events. This support has been instrumental in increasing involvement from minority communities.

A board member from Gulfport began an outreach and support group effort in her local neighborhood and church. A board member of color started a parent group with the cooperation of the Mental Health Center in Region 15. Another board member has began visiting the local elementary school to get to know some of the children with serious emotional disorders, and has initiated plans for a combined respite/therapeutic recreational program for these children and their families. Another board member of color has mediated a conflict between the classroom teacher of students with emotional disorders and parents in the Greenville school system.

The MSFAA director has been actively involved in collaborating on grant proposals that focus on underserved populations. Her presence ensured that MSFAA will be called upon to conduct training for professionals and give support to families as part of the grant objectives. One successfully funded grant, will provide money to train Jackson State University students in family support and disability issues as preparation for teaching in the special education field. Project TEACH will place regular education teachers as interns in social service agencies, including MSFAA. Another grant will provide support and education services to homeless families and their children who are enrolled in the Jackson public school system.

MSFAA has written a grant proposal to the United Way of the Capital Area in collaboration with the Reach Out Foundation and the Voice of Calvary Youth Ministries, both inner city programs, to pilot the emergency family contact/support and respite services outline in the Mississippi Department of Mental Health crisis management plan. Staff have also worked closely with Friends of Children of Mississippi (Head Start) and other state agencies to develop a KIDS COUNT proposal which was submitted to the Annie E. Casey Foundation.

MSFAA is working closely with members of the Legislative Black Caucus and the appointed members of the joint task force (37% African-American) who were involved with the legislative initiative S.B. 2626 (described under objective 7.) In February the executive director spoke to a group of case managers (for children and adults) and family members, in Mental Health Region 7. The majority of parents participating were women of color. Several were identified as key leaders for the area. The presentation was followed up with personal phone calls to these individuals. MSFAA staff has also worked with CASSP on the Embracing Cultural Diversity curriculum and participated as presenters in this 3-day training.

Objective 3: *A method to identify local parent/family controlled organizations, to foster network activities among these local organizations, and to obtain information on activities of these organizations.*

MSFAA belongs to and has working relationships with many other advocacy and professional organizations. Since April they have shared space and expertise with the Mississippi Parents & Families Network, a statewide coalition of parent groups whose main focus and expertise is around special education issues. The executive director is also in charge of project MAPP, a medical benefits access projects sponsored by the Institute of Disability Studies, a University affiliated program at the university of Southern Mississippi. The boards of both projects also share training opportunities. MSFAA also began a relationship with another new organization, Mississippi Forum on Children and Families (pre-school emphasis). The Mississippi Forum set up a legislative hotline that MSFAA utilized which enabled them to issue their own legislative bulletins faster.

Objective 4: *A system of referring family members to existing family groups or to individual family members in their geographic area and for directing parents to existing agencies with the ability to answer questions and make referrals within the service delivery system.*

MSFAA handles an average of 50 calls a month. Most case advocacy is done on the phone, but staff and board members often accompany parents to Youth Court or IEP meetings. Many professionals refer families to MSFAA and often call for advice on difficult service problems. The office manager authored a summary of the laws pertaining to ADA, section 504, and IDEA, which has been very helpful in representing children in hearings.

The regional representation (board members represent the 15 Mental Health Regions in the state) on the board has facilitated communication between local parents, the board and staff. Board members have increased parent-to-parent networking, their activities in the schools and in their local political organizations such as county boards of supervisors and local interagency councils.

The 10-week education and support curriculum, the *Developing Families as Allies Program*, co-authored by the MSFAA Executive Director, has proven to be a valuable tool for providing information and support to parents. It has been used successfully with both majority and minority parents. Forty percent of the new leaders trained in June 1993, (who then carry out the 10-week training in their local area) were women and men of color from both rural and inner city areas. A 3-day intensive training was held for 35 new parent/professional co-leaders from across Mississippi. They will lead the program in twenty towns across Mississippi in the spring and fall and will do much to build up new parent to parent support networks.

An administrative assistant was added to the staff, and the purchase of new computer equipment and software facilitated updating address lists and other communications. The raising of $15,000 cash for MSFAA, and receiving of a large contract from the latest CASSP grant has allowed expansion of office space, staff and services.

Objective 5: *An implementation strategy to strengthen the network of parents and parent organizations by increasing formal and informal contacts among groups and individuals.*

The basic structure of the Mississippi Families as Allies Network was set early on by establishing board members as key outreach coordinators in their respective regions of the state. These board members also served as contact/support persons for parents in that area. In addition, local support groups that already existed supplemented the MSFAA network structure either by becoming affiliated with MSFAA or serving MSFAA referred parents in their groups. Thus, the MSFAA Network grew to its current 22 chapters and groups.

Board meetings, workshops, conferences, the 3-day training in 1993 for parent/professional co-leaders of the *Developing Families as Allies* Program, the 10-week *Developing Families as Allies* program and the Chapter Development Manual were used to initiate local networks. A board newsletter, the *Keele Street News* and a Network Newsletter, *The Family Friend*, also fostered network cohesiveness.

MSFAA has received a contract with Mississippi CASSP to serve as state level focal point for all family and training activities associated with their new CASSP Statewide Local System Strategy Implementation project. This role involves coordinating the activities of the local CASSP Coordinating and Planning team (co-led by a local family member) at the two pilot sites. The main focus of these planning teams is to design a funding formula and develop a local system of care. Parents and other caregivers are to be included at all levels of decision-making, project development and implementation. MSFAA will assist the two pilot sites in outreach and identification of parents; providing technical assistance and support to the local parent team co-leaders; organizing and conducting a statewide training of leaders for the *Developing Families as Allies* curriculum, and staying closely involved in technical assistance and support to the leaders carrying out the 10-week *Developing Families as Allies* sessions in the pilot sites.

In June 1993, a 3-day intensive training was held for 35 new leaders of the *Developing Families as Allies* education and support curriculum, which brought together parents and professionals from across the state. They will lead the program in 20 towns across Mississippi in the fall, and will do much to build up new parent-to-parent support networks. MSFAA has also completed a Chapter Development manual, adapted, with permission, from the Louisiana Federation of Families.

In addition to activities of board members in other regions (listed under objective two), a region two parent board member has interacted with the school system so effectively she was asked to submit a proposal to better serve children with serious emotional disorders in the school district. She presented the proposal at the De Soto County Interagency Planning Council, and at their request created a survey which will be used to identify and count the number of children with serious emotional disorders in the county. MSFAA will assist her in fine tuning the survey and making it available to other regions of the state.

Objective 6: *A clearly articulated approach to providing technical assistance and support to newly forming or ongoing parent support groups, including "state-of-the-art" information on services for emotional disorders in children and adolescents, and the range of community based service options required to meet their needs.*

The *Developing Families as Allies* curriculum is one of the main tools that MSFAA uses to engage parents and to enable them to start support groups. Staff report that bringing the parents together for 10 weeks of information and skill development enhances the prospects of the group staying together and also of being effective change agents in their local community. A group of leaders for *Developing Families as Allies* was training in Louisiana in April, 1993. Louisiana has written this curriculum into their 99-660 state plan for children and families. MSFAA continues to develop pamphlets and brochures on requested service areas such as the special education referral-to-placement process, and other requested content materials.

Objective 7: *A system for ensuring timely provision of information on pending legislation, state planning processes, opportunity for providing public comment or public testimony at various administrative or legislative hearings relevant to improving services for children and adolescents with serious emotional disorders and their families.*

Five MSFAA members and officers served on the State Mental Health Planning Council for P.L. 99-660 from 1988 to 1992. Four different MSFAA members began new terms on the Council. The original members provided significant input into the State Mental Health Plan. It is expected that the new appointees will have considerable impact.

Over the course of the 1992-93 project year MSFAA was involved in the drafting, final passage, and initial implementation of a significant Child Mental Health Initiative for the state of Mississippi. MSFAA and staff from the Sisters of Mercy Health Advocacy Systems (a new grant program in Mississippi) held a meeting with the Washington Business Group on Health, agency heads, other key agency personnel, professional organizations, the Lieutenant Governor and the Speaker of the House on December 14 and 15, 1992. This meeting focussed on bringing Mississippi's children with serious emotional disturbances back to their local communities. The specific are listed below:

1. Agency heads agreed to pool the funds they are now spending out-of-state on these children;
2. Agency heads and other key players agreed to have legislation written that would mandate this compact;
3. Agency heads and other key players agreed to legislation which would mandate a managed care entity to create/contract for a local comprehensive system of care in two or three pilot sites in Mississippi. These entities will utilize blended funds which will be capitalized to better serve the child and family instead of being used as fees for service; and
4. Two small working groups were formed to complete two tasks: (1) to write a concept paper to build support and publicize efforts (written largely by the MSFAA parent coordinator); and (2) to decide which basic concepts had to be included in the proposed legislation - this group was chaired by the MSFAA Executive Director.

Media efforts included plans for a special documentary on children's mental health issues (on a local T.V. station in Jackson) and were timed to build support for the initiative.

The executive director wrote several drafts of the bill, and work with the staff attorney for the House of Representatives to complete the final version. SB 2626 passed the Mississippi legislature unanimously and was signed by the governor on March 25, 1993. Many of legislators and others involved attended a victory celebration at the home of the MSFAA Executive Director.

SB 2626 became law on July 1, 1993. This historic Child Mental Health initiative mandated an interagency agreement to pool funds currently being used for out-of-state and inappropriate in-state residential treatment for children and adolescents with serious emotional disorders. These funds will be used to develop pilot, comprehensive, individualized, systems of care using both traditional and non-categorical wraparound services in three areas of the state. Local coalitions will form management entities to operate these systems of care and deliver services based on a plan of care developed by multi-disciplinary teams which included parents of the children being served.

Policy development, planning and oversight during the implementation of this new law will be carried out by a state-level Children's Advisory Council made up of authorized appointees from the five major state child-serving agencies, the Council of Youth Court Judges, and MSFAA. The Executive Director of MSFAA was elected Chair of the CAC by acclamation.

MSFAA also worked closely with the Mississippi Department of Human Services on legislation to improve the service delivery system for children in their custody, most of whom have emotional or behavioral problems. Unfortunately, conflicts between the governor and the head of the department caused the resignation of the head of the department and restructuring of the agency, and the legislative planning was postponed.

Objective 8: *A plan to expand and develop the network across the State to include: a) ongoing Board development and leadership expansion, including regular meetings, evidence of study and decision making structure such as subcommittees, management and oversight training. Board membership and Network Members must be comprised of no less than 51% family members of children or adolescents with serious emotional or mental disorders; b) strengthening of the financial and legal independence of Network Members, including a strategy for revenue development, and timelines and specific attention to organization's legal status. If Network Members including the contractor are not incorporated, a plan and a timeline to incorporate and obtain tax -exempt status within the period of the contract award; and c) a description of the policies that address the privacy of personally identifiable data.*

From inception the board has been composed of an average of about 80% parent members and about 39% minority group members. Members are chosen to accurately represent family and children's needs and the particular demographics of the state. Most had little or no experience understanding their roles. Through trainings the board has evolved from being advisory to being more directive. In this capacity the board oversees and supports staff, directs goal and strategy development, and exercises budgetary and fiscal responsibility.

Eight new board members were added over the year. Board development is ongoing. From March 24-26, 1993 Harold Briggs of the Portland Research and Training Center, provided technical assistance and consultation to the MSFAA board, on board and committee development, and strategic planning. He also met with the executive committee regarding management plans and follow-up to the strategic planning session.

One of the goals included in the MSFAA 1990 contract proposal was to achieve organizational independence from the fiscal agent, the Mental Health Association of the Capitol Area. This occurred in April 1992. MSFAA received tax exempt status from the Federal Government in August of 1992 and a novation agreement was accepted by Center for Mental Health Services on December 1, 1992, allowing MSFAA to receive the remainder of contract funds directly. Staff moved to a new suite of offices to allow for increased staff and equipment. A three year strategic plan was developed. A survey was developed and disseminated to elicit input from the membership on this plan.

MSFAA's move to new office created additional space for parent groups and training. A flyer was sent to people on the the mailing list announcing the location of the new office, and providing basic informational materials about their goals and objectives. New computer equipment and software has greatly facilitated publicity efforts. An Ad Hoc Conference Planning Committee was convened to plan the 2nd Annual MSFAA conference which was held December 3 & 4, 1993.

The staff developed and submitted a plan to the board president to consider expanding staff and dividing project tasks into more clearly defined administrative and programmatic areas, creating the executive director was then able to complement the service delivery role of the Parent Network Coordinator. This was approved by the board in November. Loss of the Parent Network Coordinator in March accelerated the planned addition of parent volunteers to the central office. Remaining funds from the Parent Network Coordinators' salary were transferred to several other program activities. Activities receiving additional funds included funding for Parent Support Specialists to work in the central office; travel to provide technical assistance, support and case advocacy to local parents; and support for the pilot Family Support Specialist position in one area of the state.

MSFAA currently has a sub-contract with Mississippi CASSP as part of its current CASSP Statewide Local System Strategy Implementation grant. Under the terms of this contract, MSFAA coordinates and conducts Family Outreach and Education activities for the Local Level CASSP Coordinating and Planning Teams at the two project sites. In addition, MSFAA has contracts or agreements with the following entities: Mississippi Department of Health and Infant/Toddler Program; the Institute of Disability Studies, University of Southern Mississippi; Jackson State University - Project TEACH; Louisiana Federation of Families for Children's Mental Health; Mississippi Kids Count Collaborative. Subcontracts for MSFAA have been included in pending proposals with a potential award total of $70,000. Various other grant proposals are in different stages of development.

MONTANA

Family Support Network

Background

Parents, Let's Unite for Kids (PLUK) is a private, non-profit, corporation founded in 1984 by forty families. In 1986 PLUK received a federal grant to create a parent training and information center for Montana, providing support and information to families who have children with disabilities. During the past five years PLUK has grown in its capability to support families of children with serious emotional disabilities. In 1988 PLUK received funding from the Research and Training Center at Portland State University to develop training materials for parents. This resulted in *Taking Charge: A Handbook for Parents of Children with Emotional Handicaps* and two workshops on parent/professional collaboration and advocacy in the mental health system. In 1989 PLUK was one of five states receiving funds from NIMH to develop a statewide parent organization, the Family Assistance Project.

PLUK's main office is located in Billings with four regional offices around the state where four part-time Community Trainers provide services to families in their area. The Family Assistance Project began as an extension of the PLUK structure. In the 1992-93 project year the Family Assistance Project became the Family Support Network (FSN). It was incorporated as a separate organization in December 1992, and applied for nonprofit status. PLUK remains the fiscal agent for The Family Support Network and provides them with other supports such as access to an toll-free telephone line and newsletter space. Following is a summary of Family Support Network activities for the third project year (1992-93).

Objective 1: *A mechanism for providing inexpensive two-way communication with identified groups and others requesting services.*

Callers accessed the Family Support Network through the PLUK toll-free telephone line. This line was staffed eight hours per day, five days a week. If FSN staff were out of the office, PLUK staff relayed messages. Within the past year staff received an eleven percent increase in calls received via the toll-free line and saw a twenty-four percent growth and over 24% increase in names on the mailing list.

During the last quarter of the contract FSN established a contract with the Office of Public Instruction to add a second toll-free line to the office specifically to provide information to parents of children with a serious emotional disability regarding the managed care system in Montana. A small grant from the state CASSP project allowed FSN to reprint their brochure which provided more publicity for the toll-free line. A brochure concerning managed care was also being developed.

Additional publicity was provided when FSN staff were interviewed on a local television program. Staff also developed a news release for the business section of the Billings newspaper which is distributed throughout eastern Montana.

Objective 2: *A strategy to identify and engage underserved populations such as families from diverse cultural and ethnic backgrounds.*

The Family Support Network's major thrust in engaging underserved populations has been with the Native American population. During the second year of the contract FSN received a grant from the Extension Service of the Department of Agriculture to develop a curriculum for cultural sensitivity and a mental health systems guide specific to Native Americans. FSN staff presented a cultural sensitivity workshop, a mental health awareness workshop and a college credit course (presented at two tribal colleges.) Staff provided assistance regarding the grant renewal process to Native American community members.

Overall, there has been a slight increase in the number of Native Americans served by the Project, which FSN attributes to word of mouth referrals. It is clear to the FSN staff that successful interaction with tribal members depends on a long term relationship.

FSN was concerned, during the year, with the issue of Native American children in some rural communities being removed from school rather than being served appropriately. They have involved the Montana Advocacy program (the protection and advocacy agency in Montana), as well as the state director of Indian Health. In one community the rate of expulsion of Native American children with mental illness has dropped as the result of a complaint made by FSN staff and mediation provided by the state to assure appropriate services for the children of that school district. A PLUK staff member developed a workshop on this issue, which was presented to the FSN staff, and communities with large Native American populations.

Objective 3: *A method to identify local parent/family controlled organizations, to foster network activities among these local organizations, and to obtain information on activities of these organizations.*

During the 1992-93 project year four support groups were active with an average attendance of seven. The groups met on a weekly basis. Most of the individuals who provided parent-to-parent support came directly from these groups. Staff underscored the need to support and maintain groups despite the possibility of low attendance initially. Not only were FSN staff directly involved with the support groups and present at meetings, as well as providing technical assistance. In the future FSN staff hired will be parents of children with serious emotional disorders. Currently only the staff in Billings are parents of children with special needs.

FSN has developed the Family Liaison Project, which is a separate entity within FSN. This is a pilot project of parents acting as case managers for their own children. It involves six families whose children attend an adolescent day treatment program and is co-sponsored by a school district and the regional mental health center. As part of this project the fourth support group was formed, however, members of FSN and the Family Liaison Project may choose to attend either of the two support groups in Billings. Through their development of the project, FSN staff worked with state and local agencies to provide services for the six families involved. The board for the case management pilot project includes both a child and a parent of a child with serious emotional disturbance, in addition to professionals from Mental Health, Family Services, Special Education, Juvenile Justice, and a representative from the Family Support Network.

Objective 4: *A system of referring family members to existing family groups or to individual family members in their geographic area and for directing parents to existing agencies with the ability to answer questions and make referrals within the service delivery system.*

FSN's parent guide to Montana's Mental Health Services was updated using resources from a CASSP grant. This guide is very much in demand. Parent calls continue to increase, and are approximately 60% of the total calls received. It is difficult for existing staff to handle all the calls. Library materials are in almost constant use. Again, with the help of a CASSP grant, library holdings were increased by 164 items during the 92-93 project year.

FSN staff also provided training to parents using a workshop format. They present even if only one parent attends. In Billings, during October and November, FSN staff presented an eight week training course, which met once a week, for two hours, and covered skills such as advocacy, communication, school law, and coping skills.

Linking parents to support groups was successfully done on a routine basis. FSN employees assisted with the support group.

Objective 5: *An implementation strategy to strengthen the network of parents and parent organizations by increasing formal and informal contacts among groups and individuals.*

The annual conference, which focused on children with emotional disorders, was held in the fall of 1993. This year the parents were involved in the planning process to a much greater degree. A parent served on the planning council, and FSN provided scholarships, for ten to 20 parents.

The changes in the system of care in Montana will be described in more detailunder objective 7. However, FSN's involvement in the new system of managed care allowed them to increase parent contacts because the managed care team member was able to assure that a referral to FSN was made routinely for each family. On the managed care team, parents were involved in the decisions regarding treatment of their child with a serious emotional disorder and they were valued as team members. In addition, the development of the Family Liaison Project enhanced the reputation of parents as active participants in service development and delivery.

Objective 6: *A clearly articulated approach to providing technical assistance and support to newly forming or ongoing parent support groups, including "state-of-the-art" information on services for emotional disorders in children and adolescents, and the range of community-based service options required to meet their needs.*

Parents are serving in increased numbers on state and regional planning and management teams. At least one, and, in some regions, as many as three parents, serve on the Regional Managed Care teams. One parent was appointed to the state team. FSN staff and parents sit on the state Mental Health Advisory Council (3 parents). One staff member serves on the Department of Family Services Advisory Council and the newly formed Children's Mental Health Services Advisory Council is chaired by a parent.

In the first two years there was a lack of training provided by the staff for parents serving in these positions. This was remedied in the past year as through concented effort by FSN staff to review agendas, discuss proposals, and provide background information to all parents prior to the meetings. The result has been that parents have developed a reputation of being better informed about issues than the state staff. Parents have increased their participation in discussions, in setting agendas, and in organizing materials for presentations.

Objective 7: *A system for ensuring timely provision of information on pending legislation, state planning processes, opportunity for providing public comment or public testimony at various administrative or legislative hearings relevant to improving services for children and adolescents with serious emotional disorders and their families.*

The 1992-93 project year included a legislative session of the Montana legislature which meets every other year. To disseminate information, a state-wide phone tree was developed which is initiated by five calls and results in contact with two hundred people. Those contacted often called the toll free number for clarification of the information requiring FSN staff to spend more energy on it than anticipated. It did, however, successfully disseminate information about legislative activity.

FSN also increased the use of faxes to disseminate information. FSN staff arranged to use the Department of Corrections and Human Services' fax line in Helena, and with the county government's fax in Missoula. The PLUK fax number was also available at no cost in Billings.

Montana's "family of one" rule pays for psychiatric hospitalization based solely upon the child's income. The impact of this rule has been increased payment for hospitalization rather than the development of community-based services. Parents worked with two state councils to develop and support legislation which emphasized community-based services. Parents testified at the legislature to stop funding under the "family of one" rule, and ninety-seven parents called and faxed material regarding the bill to shift the emphasis to other types of services. The result of these successful efforts was that $5.4 million was earmarked for community-based care under a managed care system. State and regional managed care teams have been set up to develop services with parents involved in all the regional managed care teams. An FSN member was appointed to the state team, although issues of liability need to be resolved before she can accept the appointment. In July staff and board members attended a three day training managed care, held in Helena, as a prelude to serving on state and regional managed care teams. FSN received a contract from the Board of Crime Control to distribute information to all parents (and professionals) regarding the new managed care concept in Montana.

FSN staff increased their impact and visibility with professionals in Montana. In September 1992 FSN attended the fourth annual conference on serious emotional disorders in Great Falls where they presented and distributed the *Guide to the Montana Mental Health System*. They distributed 150 copies of the guide and had requests for more. Besides the conference, FSN provided training at five meetings, which were attended by more than one hundred professionals.

Objective 8: *A plan to expand and develop the network across the State to include: a) ongoing Board development and leadership expansion, including regular meetings, evidence of study and decision making structure such as subcommittees, management and oversight training. Board membership and Network Members must be comprised of no less than 51% family members of children or adolescents with serious emotional or mental disorders; b) strengthening of the financial and legal independence of Network Members, including a strategy for revenue development, and timelines and specific attention to organization's legal status. If Network Members including the contractor are not incorporated, a plan and a timeline to incorporate and obtain tax -exempt status within the period of the contract award; and c) a description of the policies that address the privacy of personally identifiable data.*

The board, which began 3 years ago as an advisory board, is now a policy making board of directors. The Family Support Network is incorporated and has applied for nonprofit status. This year the board members have attended two major trainings for board development, one focussing on communications skills, the second on funding services. The board has been active in seeking a grant to develop a video in conjunction with PLUK on FSN services. The board has also been active in working on the development of a foundation to increase financial independence. In the 1992-93 project year staff developed a confidentiality policy which the board approved and is signed by all staff and board members.

NEBRASKA

Nebraska Family Support Network

Background

The Nebraska Family Support Network was started in Fall of 1989 by a group of parents of children with serious emotional disabilities living in central Nebraska. These families from rural areas were concerned about the need for support services closer to their home. The Alliance for the Mentally Ill-Child and Adolescent Network of Nebraska (AMI-CAN) and Families of Children Under Stress (FOCUS) had established parent support groups in the more urban areas of Nebraska--Omaha and Lincoln. As a result, rural families began developing needed support and referral services in their own communities through the development of local support networks.

The Network began operating out of the home of the parent coordinator, in rural south/central Nebraska, until appropriate office space could be located. During the first year of the CMHS contract, the Network relied on donated space, until they were required to move. After several moves, the Network offices are now located in downtown Lincoln.

The Nebraska Family Support Network is governed by an executive board which is currently seventy-five percent parents. The advisory council, composed of parents, mental health, social service, education, health and other interested persons, operates in an advisory capacity to the Network. The Network has recently received its non-profit and tax exempt status and functions independently from its prior fiscal agent, AMI of Nebraska.

For most of the three years of the CMHC contract, the Network staff consisted of a full-time parent coordinator, Cyndi Eckhardt, and several volunteers. Toward the end of the first year of the contract a full time administrative assistant was hired to assist with day to day activities of the Network. Several persons have held this position. In September, 1993 Cyndi Eckhart voluntarily stepped down and was replaced by Melanie Knoepfle as acting executive director. At the boards request, a review of the fiscal system and an audit were initiated. Primary concerns centered on unpaid bills, back payroll taxes and unmet commitments. These were in part due to Ms. Eckhardt's ill health and to the stress of caring for her two children with emotional disabilities. The loss of her knowledge and connections with individuals has been a hardship for the organization. Following is a summary of Family Support Network activities for the third project year (1992-93).

Objective 1: *Develop a mechanism for providing inexpensive, two-way communication with identified groups and others requesting services.*

The Network provides a parent-operated, toll-free, 24 hour phone service for groups, parents, and others requesting information and referral to existing services. The telephone line is covered during the day by staff with the aid of an answering machine. At the end of the 1992-93 project year plans were underway to develop a schedule for the toll-free line to be covered by family members and volunteers. Once the schedule was set, the hours would be published in the newsletter and other public service announcements.

The Nebraska Family Network uses a variety of methods to sustain cost-efficient, two-way communication. The organization is listed in statewide telephone books. It is also listed in the Nebraska Resource and Referral System. This statewide resource system is updated quarterly.

Objective 2: *Develop strategies to identify and engage underserved populations such as families from diverse cultural and ethnic backgrounds.*

The Nebraska Family Support Network used five strategies to reach out to persons from underserved populations. First, project staff worked with the state mental health agency in an effort to gather the needed information for this objective. The plan was to have a computerized document that outlined the services of each region and the families served, including the different ethnic backgrounds. The state also required each region to assign a youth specialist as a part of their outreach efforts. Each specialist would work within the region to assess the current services and the areas of needed service.

Second, several of the Network board members were working to find persons that would be interested in joining the Network and serving as board members. They have identified persons from within the African-American and Native American communities and a person from a rural area of Nebraska as possible new board members. These new board members will play a major role in training parents and professionals in the best methods to work with families from ethnically and culturally diverse backgrounds.

Third, informational workshops were held in western Nebraska. These workshops are scheduled to provide orientation to Native-American residents of that region regarding the purpose and current functions of the Network.

Fourth, the Network is establishing a partnership and friendship with African-American communities in Eastern Nebraska. The coordinator and staff were invited to attend church and a Sunday social. This was an excellent opportunity to listen, learn and develop solid relationships.

Fifth, through extensive outreach efforts, staff identified three areas of the state with Asian populations. Asian populations are located in Omaha, Lincoln, and Grand Island. The coordinator and staff contacted the leaders of the communities on an informal basis to determine what route the Network should take that would be most effective.

Objective 3: *A method to identify local parent/family controlled organizations, to foster network activities among these local organizations, and to obtain information on activities of these organizations.*

Project staff have developed forms for the local groups to use in reporting the network activities of each group. The parent coordinator involved each group in the development and implementation phases of the new reporting system. Further, the coordinator and office staff were available to assist local groups with data collections. They were developing a training program to use during meetings with each group. The purpose of the training is to familiarize parent groups with the operations of the reporting system, explain the importance of data collection and why the information is necessary in obtaining future funding.

The Family Network has been requested to develop: (l) an obsessive/compulsive disorders support group in Kimball, Nebraska; and (2) Fetal Alcohol Syndrome training and support groups in Chadron, Scottsbluff, and Alliance.

Project staff were distributing information to all of the families on the mailing list within a 50 mile radius of the Hastings Support Group to let them know about a number of upcoming events such as public speakers, workshops, and training sessions. The Network also compiles and distributes notices for the Omaha Support Group on a monthly basis.

Objective 4: *A system of referring family members to existing family groups or to individual family members in their geographic area and for directing parents to existing agencies with the ability to answer questions and make referrals within the service delivery system.*

Staff informed family members about existing groups or families that may be near them. However, if they were only calling for information about a diagnosis and were not ready for parent-to-parent support, they were sent a newsletter. The newsletter provided further information about the Network's activities, purposes, current events, group meetings and contact persons.

When the Network finds out about new and existing support groups, group leaders are given instructions on how to get a listing in the Nebraska Resource and Referral System. These new resources are passed on to families and professionals.

The Nebraska Family Support Network's brochure has undergone revisions and 10,000 copies were mailed to identified parents, professionals, and organizations. Each new group that requested information was mailed the basic information packet and received a follow-up phone call. The Network's newsletter, *Families Matter*, is written by the board president. The mailing list has increased to 1,500 and the newsletter is printed free of charge by a law firm in Omaha.

Objective 5: *An implementation strategy to strengthen the network of parents and parent organizations by increasing formal and informal contacts among groups and individuals.*

The Network staff and board members have participated in many workshops, presentations, and conferences. The Network president was active in the planning of a statewide conference for advocacy organizations. Funds were provided for families to defray some of the expenses associated with attendance. This conference was an excellent opportunity for groups to work together and discuss ideas for the upcoming legislative and fiscal year. The conference was also an opportunity to educate other families about children and families dealing with various emotional disturbances.

The coordinator has provided two informational and humor workshops to private organizations. One workshop was held at Lincoln General Hospital with approximately 25 attending. The other was held at Richard Young Psychiatric Hospital in Omaha for information and parent/professional collaboration with approximately 12 attending.

During the last quarter Cyndi Eckhardt gave a presentation for Lincoln Public Schools with approximately 25 attending. The newsletter was distributed at this meeting and the response was favorable. The project coordinator and board members have addressed university classes.

Objective 6: *A clearly articulated approach to providing technical assistance and support to newly forming or ongoing parent support groups, including "state-of-the-art" information on services for emotional disorders in children and adolescents, and the range of community based service options required to meet their needs.*

There were no requests for assistance to develop new groups during the 1992-93 project year. The project coordinator provided training for those volunteers interested. The Network also refered families to the Parent Training Center's workshop on, "Developing and Supporting New Support Groups" which was available free of charge. The Network collaborated with other groups in the state to organize statewide conference advocacy organizations and support groups. Topics presented at the conferences included networking and a round-table on children's mental health issues.

The coordinator and other family members have met with groups and assisted in developing ideas for fund raising and maintaining support groups while the leader's family is in crisis. The Omaha Group had a fund raiser in May (Hobby Fair). People from the community rented booths to demonstrate their hobbies. The proceeds were used for social activities for children with serious emotional disturbances and their families. The Hastings group continued to meet with shared leadership. This strategy allowed family members opportunities to deal with personal and family issues.

The coordinator and staff have worked closely with the Children's Mental Health program manager and youth specialist on the development of a CASSP grant application and implementation of the National Mental Health Forum. Families were appointed to the Mental Health Congress representing all areas and ethnic backgrounds of the state. The coordinator and parents were present and participated in regional roadmap planning meetings. These meetings were held in each region and will be used at the state level for further development of Children's Mental Health Services.

The Network worked with Eagle Star, Inc. and the Native American Family Resource Center in the western part of the state to start a Family Support Worker Program. These workers are Native American individuals who are trained with information about the Department of Social Services, Supplemental Security Income, Individualized Educational Plans and other areas in which families may need assistance. The workers were available to go with the family to their meetings to lend them support and advocacy assistance. The Network helped provide the training for these workers and continues to provide technical assistance.

Objective 7: *A system for ensuring timely provision of information on pending legislation, state planning processes, opportunity for providing public comment or public testimony at various administrative or legislative hearings relevant to improving services for children and adolescents with serious emotional disorders and their families.*

During the 1992-93 project year there were many proposed budget cuts during the legislative session. It was decided that the Network would be most effective by having families contact their senators personally and provide testimony at hearings, rather than sending out a position statement. The Network maintains up-to-date information on pending legislation and informs families through the newsletter of legislation that will or may affect them. Due to the program coordinator's illness, most of the legislative information was disseminated to support groups via the newsletter. Phone calls were initiated for legislative issues that required immediate action.

The telephone tree is in place and includes families from other organizations with an interest in services for children and families. The Family Support Network also subscribes to the Nebraska Legislative Update. Agency personnel provide additional information on regulation hearings. The telephone tree has been used to encourage Senators to listen to families' concerns and vote against the proposed budget cuts.

The Network initiated a class action lawsuit on behalf of families of children with serious emotional disturbances in order to obtain appropriate services in the least restrictive settings. This lawsuit will be very important to families of children with mental health needs. A staff member gathered the initial information from families who were willing to participate and has sent it to the attorney in charge of the case. Funding for the suit has not been secured, but board members feel that this lawsuit is one of the most important actions the Network can take.

- **Objective 8:** *A plan to expand and develop the network across the State to include: a) ongoing Board development and leadership expansion, including regular meetings, evidence of study and decision making structure such as subcommittees, management and oversight training. Board membership and Network Members must be comprised of no less than 51% family members of children or adolescents with serious emotional or mental disorders; b) strengthening of the financial and legal independence of Network Members, including a strategy for revenue development, and timelines and specific attention to organization's legal status. If Network Members including the contractor are not incorporated, a plan and a timeline to incorporate and obtain tax -exempt status within the period of the contract award; and c) a description of the policies that address the privacy of personally identifiable data.*

The board of directors has become more involved with the operation of the office and finances. A number of changes have taken place in order to reorganize and become more efficient. An administrative assistant was hired who brought the organization up to date on taxes with the IRS, improved the payroll system, and applied for and received a state tax I.D. number. The office manager also revived the lending library system; retrieving books that had been loaned out many months ago. The board of directors recommended that Cyndi Eckhardt voluntarily step down from her position as executive director/coordinator and that Melanie Knoepfle become acting executive director. This allowed for a comprehensive investigation and audit of the books that took place at the end of the third project year.

Things are running much smoother and people are more satisfied with the work done in the Lincoln Office. The Omaha office has also become more involved in Network activities. The communication between the two offices has improved tremendously.

Leaders of the Family Network are utilizing internal resources to strengthen the infrastructure of the organization. The president is an attorney and has assisted with getting nonprofit status for the organization. The Network is no longer dependent on a fiscal agent. The accountant specializes in nonprofit tax and structure and continues to provide the Network with the information needed for keeping up-to-date accurate financial records.

The Network board and staff continued to explore ways of securing funding from various state agencies and grants. This included writing a grant for three more years of funding through the Center for Mental Health Services. Staff explored other foundations and organizations and fundraising continues to be a prime focus.

NEW JERSEY

S.P.A.C.E.

Background

Statewide Parent Association for the Children's Effort (S.P.A.C.E.) was organized in 1988 and received federal (NIMH) funding for one year (1988-1989) prior to the beginning of this contract. The part-time parent coordinator was Florence Warnick, who worked out of her home in East Orange, New Jersey. The organization has an active executive board that meets monthly. S.P.A.C.E. is associated with the Mental Health Association of New Jersey, which serves as its fiscal agent. Following is a summary of S.P.A.C.E. activities for the third project year (1992-93).

Objective 1: *A mechanism for providing inexpensive two-way communication with identified groups and others requesting services.*

The S.P.A.C.E. telephone number is a special line that was answered at the project coordinator's home. An answering machine was used when the project coordinator was not available. This organization does not have a toll-free line. Many telephone calls go directly to volunteer parents who served as county chairpersons in each of the many counties in New Jersey. Many parents don't have to make a long distance call because they are able to access someone in their own county.

Telephone calls as reported, declined from the first quarter to the third quarter. No figures were available for the fourth quarter. There were some difficulties with the parent coordinator's phone line during the second quarter which may have been responsible for some of the decline. Another explanation may be that more of the phone calls were going directly to the county chairpersons and not being reported via the data collection forms. Such a decentralized system of phone calls using many volunteers is a strength for the organization and consistent with the nature of the community, however it presents special challenges to data collection for evaluation that were never completely overcome.

One thousand copies of the newsletter were printed and distributed during the final project year.

Objective 2: *A strategy to identify and engage underserved populations such as families from diverse cultural and ethnic backgrounds.*

Four S.P.A.C.E. board members were persons of color. S.P.A.C.E. obtained scholarships for minority families to attend the Federation of Families Conference in November, allowing them to bring a total of eleven families, including thirteen children, to the conference. Two of the children participated on the sibling panel at the conference.

The all African American/Hispanic support group met in East Orange. S.P.A.C.E. acquired several new Hispanic members and the Monmouth County support group included Hispanics as well as persons of Asian descent.

In June two executive board members participated in the planning group of the National Association for State Special Education Directors. One issue discussed was the disproportionate number of minority children in special education. One of the S.P.A.C.E. board members presented his views about this in a written report which was included in the packet sent out to participants after the conference. One Hispanic and one African-American member of S.P.A.C.E. attended the half-day workshop on grant writing sponsored by the Puerto Rican Congress.

Two S.P.A.C.E. advocates attended a mediation case for an African-American mother in East Orange, along with an advocate from the Public Advocates Office. The mediation concerned school placement and was satisfactorily resolved with the child placed in an appropriate setting in a year-round school for autistic children.

Objective 3: *A method to identify local parent/family controlled organizations, to foster network activities among these local organizations, and to obtain information on activities of these organizations.*

New Jersey has Child Assessment Review Teams (CARTs) that include parent representation and are constituted at the county level. Members of the CARTs were sent to wraparound training put on by John Vandenburg in Pittsburgh Pennsylvania. The Department of Human Services planned to send sixty people, but had reserved only five slots for parents. S.P.A.C.E. advocated to send more parents and was successful in obtaining more slots. It was difficult, however, for parents to attend because the training was held during the week, lasted a full week, and no provisions were made to provide childcare or other support services to the families so the parent could attend.

Objective 4: *A system of referring family members to existing family groups or to individual family members in their geographic area and for directing parents to existing agencies with the ability to answer questions and make referrals within the service delivery system.*

Referrals increased during the first quarter then declined during the second quarter when there were difficulties with the phone. Referrals may have been made directly to the county chairpersons and not getting tracked. S.P.A.C.E. continued to get referrals from across the state. PIN in Pennsylvania made referrals to S.P.A.C.E. when they received a call from someone in New Jersey.

Objective 5: *An implementation strategy to strengthen the network of parents and parent organizations by increasing formal and informal contacts among groups and individuals.*

The Self-Help Clearinghouse offered to provide S.P.A.C.E. with their resource directory which lists all of the support groups in New Jersey. The Clearing House has also offered to do support group facilitator training for S.P.A.C.E. group leaders and future leaders.

The Statewide Parent Advisory Network (SPAN) asked S.P.A.C.E. to lead the panel on children with special emotional needs at their first statewide parent conference. Two family members who had not previously presented for S.P.A.C.E. were the lead presenters on that panel, increasing S.P.A.C.E.'s leadership base. One of these members, a board member, then served as a family representative at the three-day CASSP workshop in Pittsburgh, Pennsylvania.

Objective 6: *A clearly articulated approach to providing technical assistance and support to newly forming or ongoing parent support groups, including "state-of-the-art" information on services for emotional disorders in children and adolescents, and the range of community based service options required to meet their needs.*

The East Orange support group was established and increased its membership during the second quarter. The support group in Hudson county dissolved when the leader left the group. S.P.A.C.E. had some difficulty in maintaining support groups, but recognized that support happens between members in other ways and that support networks continued to exist even when a support group has stopped meeting. The Self-Help Clearing House was available to S.P.A.C.E. to do support group facilitator training for current and future support group leaders.

S.P.A.C.E. continued to do technical training for the Department of Human Services. In October staff provided a training for the Hudson CART (Case Assessment Review Team). Other counties have asked S.P.A.C.E. for help on how to serve families and for help in securing family representatives for their CART.

During the second quarter S.P.A.C.E. made a decision to no longer provide technical assistance for free except to parent groups, both because of the time and energy it takes, and because they felt that for parents to be taken seriously they ought to be paid for their services. However, S.P.A.C.E. continued to serve on the Technical Assistance Committee for the New Jersey Department of Human Services Multiservice Children's Coordinating Council (CCC) which serves as the technical assistance body to the children's planning committees known as the Case Assessment Review Teams (CARTs).

Objective 7: *A system for ensuring timely provision of information on pending legislation, state planning processes, opportunity for providing public comment or public testimony at various administrative or legislative hearings relevant to improving services for children and adolescents with serious emotional disorders and their families.*

In October budget cuts in New Jersey caused the layoffs of 500 workers from the Department of Human Services. Thousands of other employees were bumped to new jobs which resulted in disruption for some families. S.P.A.C.E. was asked to look at the Divisions in the Department of Human Services and recommend two or three budget increases for the commissioner to support. Besides taking a lot of hours of reading and research on the budget it was painful to try to make choices among many needed services.

S.P.A.C.E. was asked to review at least ten legislative bills, as their contribution to the wording of the *Bring the Children Home* bill became recognized. Staff noted where there were contradictions between these bills and the *Bring the Children Home* bill. The *Bring the Children Home* bill was signed into law in September of 1992 and stipulated development of a plan to bring children home from out-of-state placements and successfully place them, by implementing supports for them, back in their own home. S.P.A.C.E. has a seat on the committee to work on this plan, but has not always been able to attend because of transportation problems as meetings are frequently held during the day and in locations not accessible by bus or train.

The directive to look at children's issues in New Jersey prompted S.P.A.C.E. to meet with a representative of the Department of the Public Advocate regarding the needs of children with special emotional needs. S.P.A.C.E. members consistently served on eight or nine policy-making boards during each quarter. S.P.A.C.E. was invited to the induction of the Commissioner of Human Services, where the Governor and the Commissioner spoke about the importance of recognizing families.

Objective 8: *A plan to expand and develop the network across the State to include: a) ongoing Board development and leadership expansion, including regular meetings, evidence of study and decision making structure such as subcommittees, management and oversight training. Board membership and Network Members must be comprised of no less than 51% family members of children or adolescents with serious emotional or mental disorders; b) strengthening of the financial and legal independence of Network Members, including a strategy for revenue development, and timelines and specific attention to organization's legal status. If Network Members including the contractor are not incorporated, a plan and a timeline to incorporate and obtain tax -exempt status within the period of the contract award; and c) a description of the policies that address the privacy of personally identifiable data.*

The executive board continued to meet on nearly a monthly basis, with seven or eight board members attending each meeting. A member of the board, Kathy Wagner, attended the wraparound training. Another executive board member attended a three-day CASSP workshop in Pittsburgh. Family Intervention Services, one of New Jersey's mental health providers, made many of their resources available to S.P.A.C.E. They helped with looking at a budget and investigating fundraising possibilities, and enabled S.P.A.C.E. staff to attend a fundraising workshop that was very informative.

NEW MEXICO

Parents for Behaviorally Different Children

Background

Parents for Behaviorally Different Children (PBDC), a private, nonprofit, organization was formed in 1985 in response to the needs of parents of children with neurobiological disorders and/or serious emotional disabilities. This group felt there was a need for parents to share their collective experiences and support one another in obtaining services for their children. PBDC is the only parent organization in New Mexico providing support, education, and advocacy to families of children with neurobiological disorder and/or serious emotional disorders.

PBDC is directed by eight member board of directors which meets monthly. The day-to-day operations of the project were coordinated by a half-time project coordinator, Delfy Roach, from the PBDC office in Albuquerque. The consulting board to PBDC, consisting of professionals working with families of children with neurobiological disorders and/or serious emotional disorders, meets bi-monthly. Following is a summary of PBDC activities for the third project year (1992-93).

Objective 1: *A mechanism for providing inexpensive two-way communication with identified groups and others requesting services.*

PBDC installed a toll-free telephone line immediately upon receiving the NIMH contract in 1990, and shortly after, added an answering machine. The phone number was advertised in their newsletters and brochure. The coordinator and a part-time parent advocate provided support to families calling the PBDC local and toll-free numbers. Staff attended IEP and suspension meetings with families in several areas of the state, including Native American families in Thoreau and Gallup. They also accompanied parents to discharge planning meetings at psychiatric centers and correctional facilities. They have served as surrogate parents for two children in residential treatment.

PBDC also engages in other outreach to inform parents of their services. Information packets were disseminated through the schools to new parents entering the special education "behavior disordered" system; to parents and professionals calling for information; and at various workshops and conferences where PBDC has been asked to be present. Parent packets have been delivered to EPICS (Education for Parents of Indian Children with Special Needs) for distribution at their parent support meeting for those families. PBDC continued to place community service ads in state papers where they are free, and sometimes in other papers, with varying response. PBDC had displays at conferences such as the School Nurses Conference, the Young Children's Education Association State Conference, and the Multicultural State Conference.

PBDC worked with the Parent Training and Information Center, Parents Reaching Out (PRO) and their community-based advocates in the Hobbs/Lovington area to provide parents with information and support when dealing with school issues concerning children with neurobiological disorders and/or serious emotional disturbance. In October 1992 a PBDC staff member participated in a collaborative training with PRO in the southwestern part of the state, which included information on special education rights and responsibilities. During the second quarter they worked with PRO on a collaborative grant to provide assistance to children with behavioral symptoms. PBDC received referrals from PRO and collaborated with them on IEP meetings.

PBDC staff presented to families and professionals of the Moriarty (a rural community) program for three and four year olds. Information packets were distributed with information about when to seek help and what questions to ask. PBDC teamed with Montezuma Side-by-Side program (district-wide, public school program for elementary school children with severe behavior disorders to provide support to families entering their program. Collaborative meetings were held to review the material they presented to families. They refered families to PBDC for support, information, and inservices, while their counselor and social worker provided Parent Skill Building Classes for PBDC members. The first series of classes began October 20, 1992 and the second set were conducted in January and February of 1993. PBDC collaborated with the Side-by-Side Program on their IDEA-B grant application to develop a manual for teachers working in classrooms for children with behavior disorders.

Objective 2: *A strategy to identify and engage underserved populations such as families from diverse cultural and ethnic backgrounds.*

Two components of PBDC's outreach to families of diverse cultures were collaboration with existing networks working with families of color with children with disabilities, and by recruitment of culturally diverse family members to participate on their parent board. Families of color were well represented on PBDC's board.

PBDC is a referral source for Fiesta Educativa, an organization for monolingual and bilingual Hispanic families of children with disabilities. They collaborated with Fiesta Educativa on a New Mexico conference for monolingual families held in October 1993 in Las Cruces. PBDC assisted two monolingual families and one monolingual adolescent with obtaining medical, educational, and psychiatric diagnostic evaluations in Spanish. The organization's brochure was translated into Spanish, and PBDC and Protection & Advocacy collaborated on a grant to produce audio tapes about the IEP process, suspension, related services, and P.L. 94-142 in Spanish, Keres, and Navaho. PBDC provided a collaborative training in Spanish with PRO in the Anthony/Gadson area.

Packets of information in Spanish on neurological and behavioral disorders were prepared and distributed at a parent meeting in Deming and were available to parents who called. The PBDC/Las Cruces chapter was networking with Fiesta Educativa in Las

Cruces, working towards a parent center for all parent organizations to come together to assist all families regardless of disability type.

PBDC continues to work collaboratively with EPICS (Educating Parents of Indian Children with Special Needs). PBDC includes EPICS brochures in informational packet when it is going to Native American parents or professionals, and PBDC parent packets have been delivered to EPICS for distribution at their parent support meeting. PBDC also continues to work with family members of Laguna Pueblo, who are trying to keep the parent group active and to revive the support groups. PBDC has met with EPICS to discuss assisting the Laguna Group by advertising their meetings in the EPICS newsletter and by having the EPICS parent advocate (who is from Laguna) assist them.

Objective 3: *A method to identify local parent/family controlled organizations, to foster network activities among these local organizations, and to obtain information on activities of these organizations.*

PBDC and Parents Reaching Out met monthly to discuss activities, such as referrals, resources and collaborative trainings. PBDC met with EPICS, PRO, and Fiesta Educativa, consistently engaging in collaborative efforts. PBDC and EPICS were collaborating on proposals and trainings. PBDC and the Autism Project used each other as resources and referrals for families who called and needed the services. A staff member is on the board of Fiesta Educativa and on the planning committee for their statewide conference.

PBDC invited the parent liaisons and professionals in the developmental disabilities field to assist them with the Task Force to increase family/community involvement in state-run psychiatric centers. They were enthusiastic and very helpful in the meeting with the mental health professionals. The developmental disability system has parent liaisons in the neonatal intensive care units and at the various clinics at Carrie Tingley Children's Hospital. PBDC wants the mental health community to follow this model in including parents.

Objective 4: *A system of referring family members to existing family groups or to individual family members in their geographic area and for directing parents to existing agencies with the ability to answer questions and make referrals within the service delivery system.*

Families who called PBDC were referred by other parent organization, social workers, therapists, pediatricians, and school personnel, or call in response to publicity they have seen about PBDC.

Brochures were distributed to mental health professionals and hospitals to display in waiting rooms, and parent packets were available to any family requesting support and made available at support group meetings. The newsletter listed the statewide parent contacts with phone numbers for people in different areas of New Mexico. The toll-free number was also listed in the newspaper and the newspapers from PRO and EPICS.

During the first three quarters of 1992-1993 PBDC made nine referrals to family members and 47 referrals to agencies. In addition family members requested information about school related services a total of 254 times.

Objective 5: *An implementation strategy to strengthen the network of parents and parent organizations by increasing formal and informal contacts among groups and individuals.*

PBDC is working closely with Parents Reaching Out (PRO) to coordinate trainings to families statewide through Project Adobe. PBDC's part-time parent advocate assists families throughout the State and also trains other parent advocates regarding children with neurobiological disorder and/or serious emotional disturbances. PBDC has been a presenter at PRO's Stress and Coping Conference, the New Mexico Association for the Education of Young Children State Conference, inservice training for therapists and social workers at Programs for Children (outpatient unit of the Children's Psychiatric Center), and to the School-based Nurses Association.

PBDC is arranging collaborative meetings in smaller communities such as Hobbs, Lovington, Artesia, and Alamogordo between the Community Mental Health Centers, Public Schools, PBDC and families. PBDC affiliates are working hard to collaborate with other parent groups in the community to form a united front to request assistance in obtaining respite and in demanding that agencies communicate with each other so their children are better served. Each community's response is unique; for example, the Taos parents are working with community agencies to begin wraparound services in that area.

PBDC also provided information to families by making travel/registration monies available to them to attend conferences and workshops in their areas, such as workshops on ADD, Wraparound Services, the Statewide Multicultural Conference on Children and Youth and Behavioral Interventions with Children with ADHD. PBDC provided 16 scholarships to parents to attend various training and educational workshops.

Objective 6: *A clearly articulated approach to providing technical assistance and support to newly forming or ongoing parent support groups, including "state-of-the-art" information on services for emotional disorders in children and adolescents, and the range of community-based service options required to meet their needs.*

Groups that had previously been established continued to meet in Albuquerque, in Laguna Pueblo, and in Los Alamos (although this group is now dormant.) New groups began in Artesia and in Las Cruces (southern New Mexico) and continue to meet. Groups also formed in Taos (northeastern), and in Hobbs/Lovington (southeastern), but were not meeting by the end of the year. A group in Portales had requested assistance, and PBDC met with them. Even when groups weren't actively meeting, the contacts that had been established still remained. By the end of the project year there were parent groups in Albuquerque, Laguna Pueblo, Las Cruces, and Artesia. Contacts were established in Taos, Los Alamos, Portales, Hobbs, and Lovington.

PBDC provided various forms of technical support to groups. Staff kept groups informed about workshops, new information on the various neurobiological disorders and intervention strategies, and legislative and advocacy issues nationally and statewide. Staff also kept a database of support group attendance; designed and produced the flyers for group meetings; assisted with speakers; and provided phone support to group leaders about group issues, assisted them with videos, handed out materials, and sometimes attended group meetings. When a new group requested assistance PBDC staff met with interested parents to offer materials and brochures.

PBDC has sponsored other workshops and presentations throughout the state which helped bring parents together. Topics included "Developing An Appropriate IEP" at Montezuma Elementary school; "Parent Driven Services" with a speaker from Kaleidoscope and "Working with School Systems." Other speakers have presented on clinical implications of medications, the importance of occupational therapy and behavior management, and the behavioral implications of Tourette's. Childcare was provided.

Objective 7: *A system for ensuring timely provision of information on pending legislation, state planning processes, opportunity for providing public comment or public testimony at various administrative or legislative hearings relevant to improving services for children and adolescents with serious emotional disorders and their families.*

The PBDC newsletter contained legislative information. New Mexico CASSP has kept PBDC informed during the legislative session on issues that pertain to them and helped them to strategize and formulate plans to address legislative issues. The PBDC phone tree was utilized to encourage families to call school board members, legislators, senators and congress people regarding school service cutbacks, and health care for people with neurobiological disorders. PBDC continued to be actively involved in all New Mexico CASSP subcommittees, the Governor's Mental Health Council, Case Management Collaborative, Young Children's Continuum , Children's Mental Health Code Revisions, and Human Needs Council, and became involved in the Family to Family Initiative.

PBDC successfully worked through the lack of awareness of family concerns in the CASSP general committee by being persistent and present at all meetings. PBDC was the catalyst for the CASSP Task Force to increase family and community involvement in state-run hospitals. It took several rewrites of the motion to establish this task force in CASSP; and considerable energy to work through the resistance from administrators of the state-run hospitals to have the task force implemented. PBDC was successful in changing the definition for serious emotional disorders used by the division of Mental health so it now includes "neurobiological disorders and/or serious emotional disturbance or at risk of neurobiological disorders and/or serious emotional disturbance."

The New Mexico legislative session began in February 1993. The Young Children's Continuum requested one million dollars for children's mental health services. PBDC testified at the senate finance committee on this request. PBDC board members were active in writing and calling legislators. PBDC was able to advocate for systems change in educating professionals and legislators about the need for respite care for families with children with neurobiological, emotional, or behavioral differences. Specialized respite care was implemented in July of 1993, almost one year after the legislature appropriated $100,000 for respite. PBDC was routinely asked to present at conferences from the family perspective; was often consulted by case managers for assistance in the special education process; and regularly served as surrogate parents for youth who either have no family or whose family is too far away to participate in IEP and discharge planning meetings.

Objective 8: *A plan to expand and develop the network across the State to include: a) ongoing Board development and leadership expansion, including regular meetings, evidence of study and decision making structure such as subcommittees, management and oversight training. Board membership and Network Members must be comprised of no less than 51% family members of children or adolescents with serious emotional or mental disorders; b) strengthening of the financial and legal independence of Network Members, including a strategy for revenue development, and timelines and specific attention to organization's legal status. If Network Members including the contractor are not incorporated, a plan and a timeline to incorporate and obtain tax -exempt status within the period of the contract award; and c) a description of the policies that address the privacy of personally identifiable data.*

PBDC is governed by an eight member parent board of directors. PBDC also has a consulting board consisting of professionals working with families of children with neurobiological disorders and/or serious emotional disturbance.

The governing board has worked towards financial independence through collaboration with the state Office of Protection & Advocacy and EPICS on proposals. The search for foundation grants and other funding continued with the help of advisory board members and other interested parties. They have sought and received outside funding for additional staff, materials, workshops and network development.

NORTH CAROLINA

North Carolina Alliance for the Mentally Ill-Child and Adolescent Network/Federation of Families for Children's Mental Health

Background

In the fall of 1989, the North Carolina Alliance for the Mentally Ill began a Child and Adolescent Network (NC AMI-CAN). A parent of a child with an emotional disability was hired to begin the network through a two-year contract with the state's mental health division. A major goal of the organization has been to establish joint support groups, including both families of adults and families of children with mental disorders. NC AMI-CAN is part of a coalition of human services organizations whose chief responsibility has been the development of a statewide plan for the delivery of child mental health services. Funding has come from the Department of Human Services and in-kind support from NC AMI-CAN's fiscal agent, the North Carolina Alliance for the Mentally Ill. NC AMI-CAN is governed by a parent advisory council which meets bi-monthly and the board of directors of the North Carolina Alliance for the Mentally Ill. In 1992, NC AMI-CAN became the state affiliate for the Federation of Families for Children's Mental Health. Following is a summary of NC AMI-CAN activities for the third project year.

Objective 1: *A mechanism for providing inexpensive two-way communication with identified groups and others requesting services.*

All calls to either NC AMI or the Federation of Families are referred to the NC AMI-CAN Helpline. The Helpline, a toll-free phone line, is the primary source of two-way communication. The Helpline has proven to be of benefit in connecting the Parent Advisory Council (PAC) members to other parents and professionals. The PAC members have experience at the statewide system level and with their local community systems of care. The Helpline has allowed for an increase in communication between experienced NC AMI-CAN parents and parents who have only recently received a diagnosis for their child or those who have reached a point where parent-to-parent advocacy is necessary. The NC AMI Spring Conference, held in April 1993, also allowed ample time for parent-to-parent communication and contact.

A large number of parents of younger children in the two- to five-year age range are calling the project for assistance. This has enabled the Helpline Coordinator to share information regarding Early Intervention in North Carolina. Also, requests for printed materials increased considerably. Staff consistently mail out brochures, pamphlets, leaflets, and articles on childhood mental illness or serious emotional disorders. These materials are used as reference, training, and teaching tools for family members.

The North Carolina Alliance for the Mentally Ill and its Children and Adolescent Network have a joint newsletter titled *Clippings,* a name referring back to the grassroots origins of the organizations. The newsletter reaches the entire NC AMI and NC AMI-CAN mailing list of over 1,600 families and professionals in North Carolina.

Objective 2: *A strategy to identify and engage underserved populations such as families from diverse cultural and ethnic backgrounds.*

Both the president of board of directors of NC AMI and the project director of the NC AMI-CAN are members of an ethnic minority. The project is committed to diversity and has successfully recruited parent leadership from diverse communities. Project staff continue to extend outreach to the Native Americans in the state, who make up 2% of the population.

The NC AMI-CAN Project was given support to reach out to underserved populations through a new program of the North Carolina Division of Mental Health/Developmental Disabilities/Substance Abuse Services. The project was titled "Community Support Program State Service System Improvement Demonstration Project." The project goals were to identify and foster needed improvements in the mental health service delivery system; to improve linkage between consumer self-help and family support groups; and to foster the participation of minority individuals in support groups. Outreach was provided through subcontracting with statewide consumer and family groups. These groups also provided training and technical assistance in communities throughout North Carolina. Project staff also assisted the state in writing a grant proposal for the Center for Mental Health Services. This grant would enable parents and professionals to reach more minority families.

During the third project year, project staff met with a group of predominately African-American family members who were glad to discover the type of parent support that existed. Also, project staff have assisted in implementing the new Religious Outreach Network program of NC AMI-CAN. The steering committee of that program consists of 20 clergy, of which one-fifth are from minority communities. This group, designed to train clergy and congregations about mental illnesses and serious emotional disorders, presented their first program in a church with an African American congregation. Further, the Helpline coordinator is continuing to study Spanish in order to eventually reach those in the Hispanic community.

Project staff attended the National Alliance for the Mentally Ill (NAMI) annual conference in Miami, Florida. The theme was "Celebrating Diversity" and the conference honored consumers, parents, siblings, spouses, and parents of young children from all ethnic groups.

Objective 3: *A method to identify local parent/family controlled organizations, to foster network activities among these local organizations, and to obtain information on activities of these organizations.*

The strategy within NC AMI-CAN has been to strengthen existing support groups and add new groups throughout the state. In areas too rural to make support groups practical, phone trees were organized. Changes in the project director position disrupted the development and maintenance to some extent. At the beginning of 1993 there were five active support groups in the state. Subsequently, two new support groups were organized by mental health providers who turned over the leadership of the groups to family members. Many parents do not have the time or energy to participate in support groups. The PAC and staff continue to discuss ways to reach all parents.

The Parent Advisory Council members often serve as community educators. Two members from Durham have requested large numbers of printed materials regarding childhood emotional disorders to pass along to other parent networks and distribute in community workshops.

The NC AMI-CAN project manager and the Helpline Coordinator have developed some portions of a "Family Survival Manual." In order to promote a family-to-family approach to family support, this large, informative manual will provide essential information about services around North Carolina. (This manual remains incomplete but is a top priority for development.)

The executive director of NC AMI met with the staff of local community mental health centers who work with children and adolescents. The purpose of these meetings was to market the resources and support available to parents and professionals through NC AMI-CAN. He has also met with clinical staff of the University of North Carolina at Chapel Hill, Child Psychiatry Hospital to disseminate information about NC AMI-CAN.

Objective 4: *A system of referring family members to existing family groups or to individual family members in their geographic area and for directing parents to existing agencies with the ability to answer questions and make referrals within the service delivery system.*

The toll-free Helpline remains a valuable tool for referring parents and professionals to programs and services. Social workers, physicians, and school counselors are referring parents to the Helpline. Word-of-mouth and regular AMI affiliates are more actively spreading the message that the Helpline is available.

NC AMI has also provided the Helpline with a new and more powerful computer. This computer allows usage of a software program that has the capability of matching a caller's needs with local resources.

During the third project year, project staff made 27 visits to NC AMI affiliates. Their message: "Go out onto the highways and byways and bring families with young children in. They are the next generation of advocates and they need us now." More and more groups are encouraging active involvement of families of children with serious emotional disorders.

Objective 5: *An implementation strategy to strengthen the network of parents and parent organizations by increasing formal and informal contacts among groups and individuals.*

A recent re-commitment between the Exceptional Children's Advocacy Center (ECAC) and NC AMI-CAN is resulting in expanded outreach to parents. The ECAC has a mailing list of over 6,000 parents. Their newsletters will include advertisements and announcements regarding NC AMI-CAN and its Helpline. Collaboration between the Family Support Network, North Carolina Child Advocacy Institute, and the Mental Health Association Children's Program is building stronger systems for parent access.

NC AMI-CAN parents are now involved in local and state system planning committees, tasks forces, and related advisory boards. Those who live near the state capitol have accepted membership on state committees such as the Mental Health Planning Council and the Department of Public Instruction Committee. On a local level, parents are on area program mental health boards and have advocated for funding for such essentials as respite care and child care for those who attend these meetings.

NC AMI has released its "Area Program Survey," the first ranking of both adult and children's services done on a state level completed in the nation. The children's ranking gives the NC AMI-CAN parents information about available services in their local area and provides them with better tools for advocacy.

Objective 6: *A clearly articulated approach to providing technical assistance and support to newly forming or ongoing parent support groups, including "state-of-the-art" information on services for emotional disorders in children and adolescents, and the range of community-based service options required to meet their needs.*

NC AMI has started an exciting new venture in establishing the Religious Outreach Network. This network includes ministers, chaplains, and clergy from many areas of the state. The purpose of this effort (also described in Objective 2 above) is to provide educational, spiritual, and general support to families of children with mental illness.

The Child and Adolescent Network affiliates of the National Alliance for the Mentally Ill have initiated a strong campaign to educate the national organization regarding children's disorders. The NC AMI Children and Adolescents Network has a new newsletter editor, and the emphasis is directed toward inclusion, rather than exclusion, of parents of children with serious emotional disorders.

Objective 7: *A system for ensuring timely provision of information on pending legislation, state planning processes, and opportunities for providing public comment or public testimony at various administrative or legislative hearings relevant to improving services for children and adolescents with serious emotional disorders and their families.*

Over the three years of the project, there has been an observable change in the way parent advocates are regarded. Family members are now invited to join committees and family representation appears to be more important to service providers and governing agencies. NC AMI-CAN has struggled with decisions about which committees to maintain representation on and how to find parents willing to assume policy-making roles. The strongest and most active NC AMI-CAN groups are centered around the state capitol. As a result, family members have been able to maintain a strong physical presence in the legislature and state offices. Two parents testified before legislative committees, one before the Health Care Access Committee dealing with health insurance and another before the Education Committee dealing with the educational issues affecting children with special needs.

NC AMI-CAN has become part of the whole NC AMI system of legislative alert, although staff turnover in both organizations have dampened this activity. Membership or participation has been maintained in Coalition 2001, CASSP, and Robert Wood Johnson workshops and conferences; the Washington Business Group on Health; the North Carolina Coalition for Persons Disabled by Mental Illness; and the North Carolina Coalition for Mental Health Care.

A member of the NC AMI-CAN Parent Advisory Council is on the North Carolina Mental Health Planning Council. The council is well-positioned to both receive and have input in the latest information provided to the North Carolina General Assembly.

Objective 8: *A plan to expand and develop the network across the State to include: a) ongoing Board development and leadership expansion, including regular meetings, evidence of study and decision-making structure such as subcommittees, management and oversight training. Board membership and Network Members must be comprised of no less than 51% family members of children or adolescents with serious emotional or mental disorders; b) strengthening of the financial and legal independence of Network Members, including a strategy for revenue development, and timelines and specific attention to organization's legal status. If Network Members including the contractor are not incorporated, a plan and a timeline to incorporate and obtain tax -exempt status within the period of the contract award; and c) a description of the policies that address the privacy of personally identifiable data.*

NC AMI-CAN continues to exist as a project within NC AMI, which acts as its fiscal agent. A NC AMI-CAN parent is now serving on the NC AMI Board of Directors, and there are plans to encourage even more parent involvement.

The Parent Advisory Council has developed into a presence within the organization. The PAC includes a group of empowered, verbal, and knowledgeable parents who actively involve new members. Their role is to supervise the project director and to advise the NC AMI board on children's issues. Plans are underway to develop a professional resource group as an adjunct to the Parent Advisory Council. Membership in this group might include doctors, nurses, social workers, and other caregivers who wish to have input and act in a consultative role to PAC members.

PENNSYLVANIA

Parents Involved Network of Pennsylvania

Background

Parents Involved Network of Pennsylvania (PIN of PA) is an incorporated statewide organization. Although PIN of PA is incorporated and has not-for-profit status, it uses a fiscal agent, the Mental Health Association of Southeastern Pennsylvania. Christina Corp served as the project coordinator for PIN of PA. She is also the PIN coordinator for Delaware County, her home county. Under this contract, each of four regions in the state had a part-time (four hours per week) paid parent who acted as regional coordinator. Following is a summary of PIN of PA activities during the third project year.

Objective 1: *A mechanism for providing inexpensive two-way communication with identified groups and others requesting services.*

PIN of PA employed a number of strategies to maintain a viable and expansive approach to reaching large numbers of parents and professionals across the state. During the third project year, PIN of PA continued to provide inexpensive, two-way communication through its toll-free telephone line.

Project staff developed and sent publicity packets to almost 200 child-serving agencies statewide. Since that mailing in mid-February, requests were received for more information on state-wide activities. These agencies also supplied PIN of PA with updated information on the services provided through their agencies.

Objective 2: *A strategy to identify and engage underserved populations such as families from diverse cultural and ethnic backgrounds.*

During the first quarter of the project year, PIN of PA was awarded a small grant to do minority outreach and support group development in Chester City. In October 1992, PIN of PA hired a parent of color to begin this effort. A letter explaining the purpose of the grant as sent to all child-serving agencies in the Chester City area.

PIN of PA staff assisted families who live below the poverty line by providing them information on securing household appliances, applying for assistance from utility companies, securing SSI benefits, locating food distribution centers, and identifying other resources. Also, PIN of PA staff convened meetings with groups of parents from the Head Start Program, domestic abuse shelters, single parent groups, Big Brothers/Big Sisters, Youth in Action (a group of teenage parents), foster and adoptive parent groups, Alcoholics Anonymous (AA), and drugs and alcohol treatment groups to discuss PIN of PA activities. Additionally, direct assistance was provided to many of these families.

PIN of PA staff met with parent representatives from the Parent Committee of the Minority Initiatives Subcommittee of the Pennsylvania Child and Adolescent Service System Program (CASSP) State Advisory Committee. The focus of the meeting was to discuss mutual concerns and to share ideas on collaborative activities. The meeting was productive and all participants agreed to meet on a regular basis.

Objective 3: *A method to identify local parent/family controlled organizations, to foster network activities among these local organizations, and to obtain information on activities of these organizations.*

The project coordinator had regular telephone contact with the four regional coordinators and sent them up-to-date materials for distribution. Materials were also mailed to local support group facilitators on a regular basis. Upon request, information packets were provided to all new callers.

The project coordinator requested updated information on community resources, local parent groups, and advocacy organizations from the regional coordinators. This information was gathered to maintain a current listing that could be used by regional coordinators, as well as professionals, to assist families of children with serious emotional disorders. One major challenge was the time involved in collecting information and the lack of staff to gather and maintain this information on an ongoing basis.

Objective 4: *A system of referring family members to existing family groups or to individual family members in their geographic area and for directing parents to existing agencies with the ability to answer questions and make referrals within the service delivery system.*

Over the three years of the contract, PIN of PA served over eight thousand families by providing telephone support, information, referrals, support groups, and other assistance. PIN of PA referred family members to a variety of provider agencies for support groups or individual treatment.. By the end of the third project year, there were 15 parent groups in the western region, 12 in the central region, and 12 in the eastern region. Following the mass mailing to community child serving agencies, PIN of PA received an increased number of requests for brochures and literature.

In addition, PIN of PA staff were involved in numerous trainings and conferences where they distributed PIN of PA literature. PIN of PA staff used contacts at training sessions and conferences to update information from providers.

Objective 5: *An implementation strategy to strengthen the network of parents and parent organizations by increasing formal and informal contacts among groups and individuals.*

The project coordinator traveled to the western region to participate in the Living in Family Environments (LIFE) program kick-off celebrations held in Fayette and Westmoreland counties. Both of these counties received grants from the Pennsylvania Office of Mental Health to develop and expand community-based services for children with serious emotional disorders. The LIFE programs have been designed to replicate many aspects of the Robert Wood Johnson Grant that was located in Delaware County.

Delaware County, the demonstration site for implementing the Robert Wood Johnson Grant, has taken the lead in Pennsylvania for billing under Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) Medicaid services. PIN of PA staff who assisted parents in multi-agency meetings in Delaware County are being reimbursed by Medicaid for this service. Information has been disseminated to ensure that parent advocates in other counties are aware of this billing procedure.

PIN of PA staff continued to assist Pennsylvania Office of Mental Health staff with site visits to residential treatment facilities. The purpose of these visits was to ensure that family-friendly services and the CASSP principles we incorporated into the program. PIN of PA literature was always distributed during these visits. In addition, PIN of PA was invited by the southeastern regional office of mental health to participate in its annual licensing visits to family-based mental health programs in five southeastern Pennsylvania counties. The purpose of these visits was to address compliance issues, review specific services, and to model a parent/professional collaborative effort at the licensing level.

The project coordinator and the Wisconsin Family Ties project coordinator (Maggie Mezera) presented a paper entitled "Two Models of Robert Wood Johnson (RWJ) Mental Health Services Program for Youth Projects Using Parents as Advocates in Pennsylvania and Wisconsin" in January 1993 and again in March 1993. Further, PIN of PA was able to accumulate resources from a variety of areas so that five additional parents were able to attend the March 1993 conference in Tampa. Pennsylvania held its annual statewide CASSP conference in March 1993 entitled "An Interagecy Approach to School Based Mental Health Programs." PIN of PA staff and other parents attended, with some staff involved as presenters and panel participants.

The project coordinator was invited to a conference, sponsored by the Alliance for the Mentally Ill of Pennsylvania (AMI of PA), on managed care to address the impact that this would have on children's services. The feedback from participants regarding the conference was positive. PIN of PA continues to strengthen their alliances with AMI of PA.

The central region coordinator planned a Fall 1993 conference which will be co-sponsored by PIN of PA and nine central region county CASSP programs. Topics include parent/professional collaboration, special education issues, and related mental health concerns. Further, York County staff and volunteers held a one-day conference in the spring of 1993 to address children's mental health issues. A board member from that area represented PIN of PA and distributed information packets.

Objective 6: *A clearly articulated approach to providing technical assistance and support to newly forming or ongoing parent support groups, including "state-of-the-art" information on services for emotional disorders in children and adolescents, and the range of community based service options required to meet their needs.*

Support group start-up materials and direct assistance were provided by the project coordinator and regional coordinators to newly forming and on-going groups. New parent contacts were identified in Mercer and Northampton counties.

Negotiations were held with Montgomery County to hire a parent advocate. Fayette County used funds from the LIFE grants to contract with three parents to provide support and advocacy services to parents in that community. Further, Berks County hired a part-time parent advocate who provided PIN of PA staff for several hours of technical assistance and reviewed materials in the PIN of PA Resource Center. The parent advocate from the Philadelphia LIFE Project also met with PIN of PA staff for technical assistance.

Objective 7: *A system for ensuring timely provision of information on pending legislation, state planning processes, opportunity for providing public comment or public testimony at various administrative or legislative hearings relevant to improving services for children and adolescents with serious emotional disorders and their families.*

PIN of PA staff and members attend the Pennsylvania Mental Health Planning Council Meeting in November. The PIN of PA executive director has been appointed as a co-chair of the Council and the project coordinator is the co-chair of the Children's Subcommittee. PIN of PA has participated on the Planning Council since its inception in 1988.

PIN of PA staff continue to serve on a variety of committees and councils that address children's mental health policy issues. These committee include: Pennsylvania Managed Care Task Force, Pennsylvania CASSP Advisory Committee, Transition Coordinating Council, the Governor's Commission on Children and Families, Commonwealth Children's Coalition, Pennsylvania Protection and Advocacy Board of Directors, and Pennsylvania Association for Retarded Citizens. In addition, PIN of PA presented testimony at two public hearings sponsored by the Pennsylvania Transition Coordinating Council and the Pennsylvania Managed Care Task Force. PIN of PA responded to a call for responses from the Pennsylvania Secretary of Welfare on managed care.

PIN of PA staff have participated in two meetings with Deputy Secretary Ford Thompson, Pennsyvania's Mental Health Commissioner. The first was an information dinner meeting to familiarize him with PIN of PA activities. PIN of PA staff also shared concerns and raised questions regarding children's mental health services and the pending proposed mental health budget. The second meeting occurred after the budget was released and the discussion revolved around the dispersion of $4 million of additional funds in the proposed budget for community mental health services for children , adolescents and their families. These funds were earmarked for expansion of LIFE projects. PIN of PA Staff requested that the state mandate specific community services for children and adolescents with these money. Parent support and advocacy through individual county contracts were raised as a priority service. It was strongly suggested that counties be encouraged to have similar meetings including PIN of PA staff, Pennsylvania Office of Mental Health staff, and relevant county mental health administrators.

Objective 8: *A plan to expand and develop the network across the State to include: a) ongoing Board development and leadership expansion, including regular meetings, evidence of study and decision making structure such as subcommittees, management and oversight training. Board membership and Network Members must be comprised of no less than 51% family members of children or adolescents with serious emotional or mental disorders; b) strengthening of the financial and legal independence of Network Members, including a strategy for revenue development, and timelines and specific attention to organization's legal status. If Network Members including the contractor are not incorporated, a plan and a timeline to incorporate and obtain tax -exempt status within the period of the contract award; and c) a description of the policies that address the privacy of personally identifiable data.*

PIN of PA staff are engaged in ongoing discussions with the Pennsylvania Office of Mental Health Children's Bureau to discuss the goals and mission of PIN of PA. Project staff have raised the need for financial assistance to expand and support the organization. Discussions have also included the possibility of PIN of PA being the gatekeeper for parent scholarship funds (as well as developing the criteria to receive scholarship funds).

A strategic planning session for the board and staff was facilitated by Harold Briggs, Ph.D. from the Research and Training Center on Family Support and Children's Mental Health at Portland State University. He met with PIN of PA to assist in clarifying their mission, goals, objectives, and activities for a three-year period. A comprehensive outline and plan were developed by the conclusion of the three-day meeting.

TEXAS

Project TX-Net

Background

The TX-NET project is one of several projects under the umbrella organization Partners Resource Network, Inc. Partners, a private non-profit organization, began in 1986 and is governed by a five-member board that meets quarterly. Several of the board members are parents of children with disabilities. Partners is the statewide Parent Training and Information Center of Texas and is funded by federal and state grants, contract, private foundations, and donations. The Partners office is located in Beaumont in the southeastern part of the sate. There are nine regional offices located around the state.

The TX-NET project was staffed by a three-quarter time project coordinator, who was responsible for carrying out the activities of the contract with support from Partners staff. For various reasons, the person holding the position of project coordinator changed several times during the life of the project. The TX-NET project had an advisory council made of up parents of children with serious emotional disorders. This council assured the focus on children and adolescents with emotional, behavioral, and mental disorders and provided input into the development of the project activities. Toward the end of the contract period, the project advisory council evolved into a working board with increased responsibility for the direction and evaluation of the project. Following is a summary of TX-NET activities during the third project year.

Objective 1: *A mechanism for providing inexpensive two-way communication with identified groups and others requesting services.*

Parents could contact the TX-NET Project by: (1) calling a toll-free phone line; (2) mailing back a portion of the brochure; or (3) calling one of the parent volunteers. By the end of the third project year, community and state programs and agencies were increasingly referring parents to the project. Other methods of communication with parents included a quarterly newsletter, periodic updates and alerts, an annual conference, and an annual parent leadership training.

The toll-free phone line, which serves all of the Partners projects, was available 24 hours each day and was answered by an answering machine when staff were not available. Parents calling the toll-free number were referred to a staff or volunteer who lived near them. To assist families from Spanish-speaking backgrounds, a parent who was bilingual in English and Spanish was available one day a week. Further, the winter edition of the newsletter, *Pathways,* was published and disseminated in February. Parents contacting the project for the first time were given a complimentary subscription if they were unable to pay.

The TX-NET brochure advertising the toll-free phone line was disseminated to a variety of groups and individuals including: l) staff and volunteers related to other Partners projects (approximately 200 individuals); 2) 35 newly-recruited volunteers for the TX-NET community resource liaison network and the TX-NET Advisory Council; 3) newly forming parent support groups in Dallas (urban and minority families), Greenville (rural), and Sherman (rural); 4) 215 selected community mental health centers throughout the state; 5) 371 school districts, regional service centers, and special education cooperatives in the state; and 6) members of the children's mental health plan programs in Fort Worth, McAllen, and Amarillo.

Objective 2: *A strategy to identify and engage underserved populations such as families from diverse cultural and ethnic backgrounds.*

Staff from the Partners Resource Network provided extensive support in reaching underserved populations. An outreach specialist was hired to work collaboratively with the TX-NET project coordinator to engage ethnically diverse populations. Outreach efforts were targeted in urban locations such as San Antonio, Austin, and Dallas. The resource manager provided assistance in developing printed materials and canvassing the state for in-kind resources. The bilingual outreach specialist provided assistance in translating printed materials into Spanish.

Project staff recruited two African-American and two Hispanic parents to serve on the TX-NET Project Advisory Council. Further, staff recruited three ethnically diverse family members to serve as community resource liaisons; two of them were African American and one was from an Hispanic background. Each of these parents received stipends and attended leadership training workshops. Further, the community outreach specialist of from Partners assisted in recruiting minority parents for the Project Advisory Council and the network of community resource liaisons.

The project coordinator assisted a newly forming support group for African-American parents in the Dallas area. Through her efforts, the groups have agreed to recruit and welcome members whose children have emotional, behavioral, or mental disorders. Parent volunteers provided a "warm line" for this group. Project staff assisted the group by producing and printing public awareness posters to be placed in two large public health hospitals. The posters focused on African-American families concerned about their children's behaviors and confused about where to get help.

Objective 3: *A method to identify local parent/family controlled organizations, to foster network activities among these local organizations, and to obtain information on activities of these organizations.*

Volunteers and several family-controlled organizations were identified. This information was shared with parents and professionals calling the toll-free number. Further, contacts were made with these parent leaders and organizations through individual telephone calls and at state and regional meetings and conferences attended by the project coordinator. Contact was made with seven statewide membership organizations, including the Alliance for the Mentally Ill-Child and Adolescent Network and the Federation for Children's Mental Health to invite them to participate on the Project Advisory Council.

Stipends were provided to six parent leaders to attend the parent leadership development training and the annual conference of parent training institutes. Further, information on the activities of several support groups was published in the calendar of events in *Pathways.*

Objective 4: *A system of referring family members to existing family groups or to individual family members in their geographic area and for directing parents to existing agencies with the ability to answer questions and make referrals within the service delivery system.*

The TX-NET project utilized support groups and parent-to-parent contacts as a means of providing support to family member. The parent-to-parent contacts were always intended to be handled by community resource liaisons. This activity was not adequately addressed until the third project year, when a network of 16 parents representing various interests, ethnic groups, socioeconomic levels, and other demographic characteristics were recruited and trained. Prior to this, most parent calls were handled by TX-NET or Partners staff and volunteers.

Partners staff provided training and assistance regarding services available from public education. They also assisted the project coordinator by attending Individualized Education Plan (IEP) meetings and staffings with parents.

Objective 5: *An implementation strategy to strengthen the network of parents and parent organizations by increasing formal and informal contacts among groups and individuals.*

TX-NET Project participated in the development of nine new parent support groups in the state, including one group primarily focused on the needs of African-American families. Project staff conducted an annual parent leadership workshop for parent volunteers and community resource liaisons. Newsletters of local and statewide organizations were sent to family members. Further, a part-time staff person, with the title of family resource coordinator, was hired to assist with project activities, including data collection on support groups across the state.

During the first two years of the contract, the project made an unsuccessful attempt to establish a consortium of statewide membership organizations. In the third project year, the concept was modified to a network of key individuals from across the state with a variety of interests. This network included the community resource liaisons and the members of the Project Advisory Council.

The project coordinator attended an average of eight to ten meetings per month on the local, regional, and state level. The state level Mental Health Planning Advisory Council for the Texas Department of Mental Health and Mental Retardation coordinated the development of the state application for mental health block grants for Texas. The project coordinator participated in the development of the grant application and was one of the two members of the Council to represent parents of children with serious emotional disorders. The project coordinator was involved in on-going and extensive planning, training, and evaluation activities with several local school districts.

Objective 6: *A clearly articulated approach to providing technical assistance and support to newly forming or ongoing parent support groups, including "state-of-the-art" information on services for emotional disorders in children and adolescents, and the range of community based service options required to meet their needs.*

Several publications were developed during the life of the contract. A fact sheet titled "What Is a Support Group?" was developed to help families with less time-consuming, informal support groups. Each edition of *Pathways* included informational articles for families of children and adolescents with emotional disturbances. A "Facilitator's Manual" was developed and disseminated to local support groups and to regional staff of Partners. A "Reference Manual" on topics related to emotional disorders was developed by the Partners staff and copies were disseminated to all staff, volunteers, and members of the Project Advisory council. A handbook was developed for use by members of the TX-NET Advisory Council and the community resource liaisons.

Support groups requested and were given information and technical assistance regarding state-level legislative activities, educational rights, status of the children's mental health plan in Texas, and the problems faced by families of children with emotional, behavioral, or mental disorders. Specific content areas included accessing services from public agencies, dealing with expulsion, and addressing inappropriate discipline.

Objective 7: *A system for ensuring timely provision of information on pending legislation, state planning processes, opportunity for providing public comment or public testimony at various administrative or legislative hearings relevant to improving services for children and adolescents with serious emotional disorders and their families.*

Two strategies were used to accomplish this objective: (1) participation in a statewide consortium for legislative action; and (2) membership on committees and task forces.

Partners is a participant in the Texas Disability Policy Consortium. During legislative sessions, this consortium publishes a weekly legislative update that informs consumers about legislative activities. The TX-NET project coordinator reviewed these legislative updates and disseminated them to key network members. Parents were encouraged to join the consortium as individuals. Legislative alerts from the Mental Health Association and the Alliance for the Mentally Ill were also mailed to key volunteers.

The project coordinator and other parent leaders were active members of a number of state-level planning committees and advisory groups. The project coordinator participated on the Operations Planning Committee for Mental Health Services, Children's Mental Health Planning Council for PL 99-660, the Children's Bill of Rights Task Force, and the Mental Health Planning Advisory Council for Texas Mental Health and Mental Retardation.

Objective 8: *A plan to expand and develop the network across the State to include: a) ongoing Board development and leadership expansion, including regular meetings, evidence of study and decision making structure such as subcommittees, management and oversight training. Board membership and Network Members must be comprised of no less than 51% family members of children or adolescents with serious emotional or mental disorders; b) strengthening of the financial and legal independence of Network Members, including a strategy for revenue development, and timelines and specific attention to organization's legal status. If Network Members including the contractor are not incorporated, a plan and a timeline to incorporate and obtain tax -exempt status within the period of the contract award; and c) a description of the policies that address the privacy of personally identifiable data.*

TX-NET remained a project of the Partners Resource Network throughout the three years of the contract. During the third project year, the project coordinator provided intensive technical assistance to a core group of parents from the local community to assist them with leadership development. As a result, the group formed a board of directors, developed by-laws, and applied for incorporation as a non-profit agency. These activities were viewed by the co-directors of Partners as steps toward developing a competing organization and considered inappropriate use of TX-NET funds. The project coordinator then chose to leave TX-NET and join the newly formed organization. During this time there was much conflict and confusion over how to assure that the focus of the project remained on children with serious emotional disorders while at the same time existing within an organization with a focus on multiple disabilities.

A third project coordinator was hired with five months left in the third project year. The priority of this coordinator was the restructuring of the Parent Advisory Council. Twenty targeted parent leaders were invited to participate on the council. Parents were recruited from the following groups: Alliance for the Mentally Ill (AMI), Federation of Families for Children's Mental Health, Attention Deficit Association, Autism Society, Traumatic Brain Injury Foundation, Tourette's Syndrome Association, Texas Education Agency, Learning Disabilities Association, and local community mental health plans of Texas. Particular attention was given to representation of African-American and Hispanic families and families from both rural and urban settings.

VERMONT

Federation of Families for Children's Mental Health

Background

The Vermont Federation of Families for Children's Mental Health has been in existence since 1989, functioning with small grants from the Vermont Child and Adolescent Service System Program (CASSP) project and more recently with a contract from the National Institute of Mental Health (NIMH). Judy Sturtevant is the parent director and has served in that position since the organization's inception. There are ten Social and Rehabilitative Services catchment areas in Vermont; each has a community mental health center and a related interagency team that includes a parent representative. The board of directors of Vermont Federation of Families is composed of these parent representatives. At the beginning of the grant the Vermont Federation of Families had recently incorporated as a private, not-for-profit organization. Prior to this the Vermont Association of Mental Health served as the organization's fiscal agent. Following is a summary of Vermont Federation of Families activities for the third project year (1992-93).

Objective 1: *A mechanism for providing inexpensive two-way communication with identified groups and others requesting services.*

The Vermont Federation of Families continued to maintain their toll-free line for parents. Over the course of the year they received an average of 119 phone calls per month. A computerized database was developed to collect data on incoming calls and was fully utilized by the third quarter of the year.

The second issue of their newsletter, *Families First in Vermont*, was published at the beginning of the third quarter. The cost of publishing *Families First in Vermont* was greater than originally estimated, and at times it was difficult to have participation from outside authors. However, those obstacles were overcome and resulted in a publication that has received national recognition. The newsletter provided state-of-the-art information at a fifth-grade reading level, making it accessible to most families. There are now over a thousand contacts on the Vermont Federation of Families mailing list.

The publication *The State of Children's Mental Health* was a cooperative venture between the Vermont Federation of Families and the Vermont Association for Mental Health. Three to four issues were published each legislative session to apprise families, service providers, and concerned citizens of the significant strengths and weaknesses in the service delivery system and its status for financial support from the state administration.

Objective 2: *A strategy to identify and engage underserved populations such as families from diverse cultural and ethnic backgrounds.*

The federation's attempts to create a dialogue with the Abenaki (Native American) community resulted in little success. So far, the federation's most significant outreach has been through their brochure and newsletter. However, the new respite care coordinator for Franklin Grand Isle County, where the Native American community resides, is also a therapist to that community. It was hoped that contact with her through the Respite Care Project (described below) would enable the statewide family network to provide more information to Native Americans and eventually create a stronger dialogue.

Objective 3: *A method to identify local parent/family controlled organizations, to foster network activities among these local organizations, and to obtain information on activities of these organizations.*

Using the available parent representatives on the local interagency teams was an advantage in developing a local level network. An initial training was done by the staff at the Vermont Federation of Families, followed by the parent members recruiting and training other families to sustain and energize the network. Prior to the Vermont Federation of Family's existence, there were three fledgling parent groups that did not know of each other's existence. Over the course of the three years, local parent groups have grown to 11, which are connected with each other through trainings, workshops, conferences, and the resources of the Vermont Federation of Families.

It proved difficult to create local networks in two of the regions (Lamoille and Rutland) due in part to the makeup of the regions and the lack of consistent parent representation in those areas. This forced the director of the Vermont Federation of Families to do a lot of individual networking in those areas. While individual families have been linked together during the three years, no group has been sustained in these regions.

The Educational Series for Families in the Lamoille County area began in October 1992. Two families participated. Because the two families were very different in terms of ages of the children involved and the issues they were facing, this did not evolve into a support group as was hoped.

Objective 4. *A system of referring family members to existing family groups or to individual family members in their geographic area and for directing parents to existing agencies with the ability to answer questions and make referrals within the service delivery system.*

When a parent called the Vermont Federation of Families office, a short data collection sheet was completed, indicating the nature of the issues that are of concern. Based on that information a parent may have been connected to another family with a similar situation. Permission was obtained from both families before this connection was made.

The Vermont Federation of Families continued to receive requests for referrals through their regular and toll-free phone lines. These included requests for referrals for services, for information about the respite project, and requests for referrals to support groups. The majority of requests were for someone to accompany them to meetings (school, mental health, court hearings) to help them advocate for their child.

There were a total of 499 calls requesting information or referral to services during the final year, 130 calls about respite care, and 316 requests for clarification or assistance with the service delivery system. A total of 24 family members were referred to support groups.

The Vermont Information and Training Network is the federation's biggest referral source. Other referrals come from the staff of the ten community mental health centers, the Department of Mental Health and Mental Retardation, the Department of Education, the Department of Social and Rehabilitative Services, the Parents' Assistance Line, Parents Anonymous, Parent-to-Parent, and individual family members.

Objective 5: *An implementation strategy to strengthen the network of parents and parent organizations by increasing formal and informal contacts among groups and individuals.*

A workshop on severe emotional disturbance was held in November 1992 in collaboration with the Vermont Parent Information and Training Center. Fifteen persons attended, representing providers, advocates, and family members. A collaborative teaming training was held in October 1992 for all members of the local interagency teams and the state Interagency Team. The training was presented by staff at the University of Vermont and helped the teams to focus on how well they cooperate and collaborate on behalf of children and their families, and on the relationship of the local interagency teams to the state Interagency Team.

The first statewide respite care conference was held on January 29, 1993 with Richard Donner as the keynote speaker. The conference was well-attended by families, children, and professionals. Respite care was provided by staff of the Department of Mental Health and Mental Retardation. The quarterly statewide respite coordinators meeting was held in September 1993. The agenda included a discussion of future advocacy needs for the continuation of respite care for children with severe emotional disturbance.

The Vermont Federation of Families created the first video series in the state on the training of respite care workers in the provision of care to children and youth experiencing a severe emotional disturbance. National experts, local providers, children, and families were featured on seven 42 minute tapes along with a training, evaluation, and study packet. This series came about at the request of the respite coordinators who had been training workers with the respite care manual introduced at the beginning of the project. Each of the ten community mental health centers had its own set of video tapes.

Even before completion, the federation had requests for copies of this videotape series from other states.

Objective 6: *A clearly articulated approach to providing technical assistance and support to newly forming or ongoing parent support groups, including "state-of-the-art" information on services for emotional disorders in children and adolescents, and the range of community based service options required to meet their needs.*

The first "Train the Trainers" workshop for a sibling support network was held in October 1992. Twenty adults were trained along with 30 siblings of children with disabilities. Subsequently several local sibling support networks have begun around the state. This training was done in collaboration with Parent-to-Parent of Vermont and with the Vermont Parent Information Center.

During the past year, the local level networks continued with their regular meeting schedule. The Vermont Federation of Families paid for respite workers from the Vermont Respite Project to provide on-site child care in some local networks.

Objective 7: *A system for ensuring timely provision of information on pending legislation, state planning processes, opportunity for providing public comment or public testimony at various administrative or legislative hearings relevant to improving services for children and adolescents with serious emotional disorders and their families.*

The publication *Legislative Alert*, which is coauthored by the Vermont Federation of Families and the Vermont Association for Mental Health, was begun and published three times during the legislative session, January - May 1993.

The Vermont Federation of Families assisted in recruiting bipartisan support for introduction of a cross-disabilities family support bill during the legislative session. No action could be taken during the session, but the Summer and Fall were spent strengthening their position for the next session. Staff of the Vermont Federation of Families attended the"Family Support Conference" held in Albany, New York in order to talk with individuals from other states that have passed family support legislation.

The Vermont Federation of Families staff continued to serve on the Substance Abuse and Mental Health Subcommittee of the Vermont Health Care Authority. The mission of this group was to develop two models for universal access to health care in Vermont: a single payer model and a multi-payer model. Their presence helped insure that children's mental health would be adequately covered in both models. Staff and families testified on children's mental health in relation to long-term health care at a hearing held by the Health Care Authority. As a result, the Vermont Federation of Families will serve as an editorial reviewer for a health care report on children's mental health in long-term care. Federation members also attended meetings and authored sections of Vermont's Mental Health Plan. The director was part of a state delegation to the CASSP Financial Planning

Regional Meeting in Bedford, New Hampshire, where she received information on the options for the nation's future health care reform.

Staff of the Vermont Federation served on a subcommittee that was part of a larger initiative to overhaul Vermont's System of Care for Children and Youth Experiencing a Severe Emotional Disturbance. This system of care is mandated under ACT 264 that is reviewed each year, and a set of priorities established and presented to the legislature. The larger committee was broken down this year into smaller subcommittees to more thoroughly scrutinize Vermont's plan.

Staff and a board member participated in a mini-retreat with similar family support projects in upstate New York. They shared with each other what they have learned and brainstormed on how to overcome the obstacles they were experiencing.

Objective 8: *A plan to expand and develop the network across the State to include: a) ongoing Board development and leadership expansion, including regular meetings, evidence of study and decision making structure such as subcommittees, management and oversight training. Board membership and Network Members must be comprised of no less than 51% family members of children or adolescents with serious emotional or mental disorders; b) strengthening of the financial and legal independence of Network Members, including a strategy for revenue development, and timelines and specific attention to organization's legal status. If Network Members including the contractor are not incorporated, a plan and a timeline to incorporate and obtain tax -exempt status within the period of the contract award; and c) a description of the policies that address the privacy of personally identifiable data.*

The executive committee of the Vermont Federation of Families and the board of directors each met eight times during the year, with seven of the eight meetings occurring in the first six months of the year, and the final one in September 1993. This final meeting was a day-and-a-half retreat involving staff, board members, Ken Libertoff of the Vermont Association for Mental Health, Brenda Bean, Coordinator of the Robert Wood Johnson Foundation Project, and a parent facilitator from a different state. During the retreat the organization's mission was clarified, a long-range strategic plan was started, and committee assignments were made.

Consultants were used by the Federation to strengthen the organization. The director met with a consultant to nonprofit organizations on strategies to strengthen the infrastructure and promote their independence. An attorney was hired to assist the board in legal matters pertaining to the federation as a nonprofit organization, and to finalize their application for nonprofit status. During the final quarter of the contract, the federation received a positive determination on its 501(c)(3) nonprofit status.

The Vermont Federation of Families continues to oversee the implementation of the respite project. This project was designed and implemented by the Vermont Federation of Families, and is a statewide project to provide respite care via Vermont's ten community mental health centers. This project served 135 families. During 1992-93, staff worked with an independent consultant to do a first-year evaluation of the project under its new grant funding, with the evaluation to include feedback from families, respite workers, respite coordinators, and community mental health center staff and administration. During the third quarter, the continuation proposal for a third year of funding for the respite care project was completed and submitted.

The Vermont Federation director and the project manager of the respite project gave a presentation on Vermont's respite model at the annual respite conference in Washington, D.C., resulting in many requests for literature, videos, and more information. They gave another presentation as part of a wraparound conference in Burlington, VT. The audience was made up largely of Canadians looking to implement a respite care project in Toronto. In addition, the Vermont Federation of Families was approached regarding the inclusion of Vermont's respite model in a grant proposal to do a training in Moscow.

VIRGINIA

Parents and Children Coming Together

Background

Parents and Children Coping together (PACCT) began in 1985 when a local Richmond, Virginia, support group of parents of children with emotional disabilities organized and incorporated. In the early stages of PACCT's development, their funding came primarily from donations and in-kind contributions from public and private sources. In 1988, PACCT was awarded a grant through the Research and Training Center on Family Support and Children's Mental Health at Portland State University as one of the first five states to receive a statewide parent organization demonstration grant. In 1990, when the demonstration project were completed, Virginia Child and Adolescent Service System Program (CASSP) agreed to fund a part-time coordinator for PACCT. This close relationship with CASSP continues today.

PACCT, a private nonprofit organization is governed by a diverse 14-member board that meets six times a year. Prior to its incorporation, the Mental Health Association of Virginia served as its fiscal agent. Board members were recruited from the support groups throughout the state. The day-to-day activities of PACCT have been run by a part-time executive director, Joyce Kube, who has been assisted by a part-time parent coordinator. The organization's offices are located at the Mental Health Association. Following is a summary of activities during the third project year.

Objective 1: *A mechanism for providing inexpensive two-way communication with identified groups and others requesting services.*

PACCT has maintained two phone lines and has an answering system in place. A toll-free line was added as a part of this contract to facilitate calls from areas outside of Richmond.

During the third project year, PACCT received calls from around the Commonwealth, with many from Richmond, as well as calls from northern Virginia and Fredericksburg. By the end of the project year, many calls were being received about the implementation of the state Comprehensive Services Act and its impact on services for children with emotional disorders. Out-of-state calls came from as far away as Maryland, North Carolina, South Carolina, Texas, and Tennessee. Most of the out-of-state calls were from professionals looking for information and materials so that they could replicate PACCT's programs.

Objective 2: *A strategy to identify and engage underserved populations such as families from diverse cultural and ethnic backgrounds.*

PACCT has been involved in a five-year collaboration with the Annie E. Casey foundation that focuses on providing culturally appropriate services to families living in the east-end area of Richmond. Through this project, PACCT hired a parent coordinator and began the task of establishing parent support groups in the east end. This work involves the recruitment, retention, and training of parents, and the inclusion of parents in the Richmond Urban Mental Health Initiative.

PACCT sponsored four minority parents to attend the Federation of Families for Children's Mental Health annual meeting in November 1992, in Arlington. Further, staff visited two support groups which were primarily African-American to provide support and technical assistance. An African-American group leader sponsored a workshop with Karl Dennis. Eighty-five people attended (capacity was 75) and it was a tremendous success. PACCT's major activity related to minority outreach occurred during the Alliance for Increased Mental Health Awareness (AIM) anti-stigma campaign. Having Earl Campbell, a member of the Football Hall of Fame, facilitate the kick-off campaign resulted in a lot of media coverage. This speaker provided his multicultural perspective on mental illness. Photographs of Mr. Campbell with the governor (who is African-American), and with children from a school in Richmond (the student population is 90% African-American) were used as a display.

PACCT has also increased its minority outreach by working with AIM in their anti-discrimination campaign. This was done through a booth at the "A Day in the Park with Friends" event. Lollipops and bookmarks attracted children while the parents who followed them were able to pick up the brochures and ask questions. The theme of the anti-discrimination campaign was "Mental Illness Doesn't Discriminate; Why Should You?" Literature was given to over 200 African-American parents. City Child and Adolescent Mental Health employees were available to answer questions.

Objective 3: *A method to identify local parent/family controlled organizations, to foster network activities among these local organizations, and to obtain information on activities of these organizations.*

The project director attended a host of network development meetings. Some of her contacts were sustained through an Interagency Consortium meeting that was held at least quarterly. She attended meetings with Child and Family Services, Youth Assessment Teams, SAMHSA, and with Dr. Singh of Commonwealth Institute, among others. During the fourth quarter, the project director met with 23 other groups and made a presentation at the Virginia Commonwealth University School of Social Work regarding advocacy and current legislative issues.

Project staff met with the Richmond-based Mental Health Law Project around SSI issues and with a larger group of concerned organizations, with a focus on disseminating information to families regarding SSI regulations. The same staff member also met with the Department of Rights for Virginians with Disabilities about their plans for reorganization. Further, there were four PACCT parent members on the 99-660 Planning Council, along with several Alliance for the Mentally Ill (AMI) parents.

Carol Obrochta, a PACCT parent, provided the keynote address at the annual community services boards meeting, stressing the needs of families of young children. She also met with the Virginia Alliance for the Mentally Ill director regarding working together on family support issues. Both organizations are strengthening their interorganizational referral arrangements.

PACCT has maintained an extensive library of books and video tapes that may be used by parents. In addition, PACCT has published the quarterly newsletter *Parent Watch*. The mailing list for this newsletter consists of over 1200 families and professionals which reflects its consistent growth.

Objective 4: *A system of referring family members to existing family groups or to individual family members in their geographic area and for directing parents to existing agencies with the ability to answer questions and make referrals within the service delivery system.*

When families called the PACCT office, the staff assessed the needs of the family member calling and made the appropriate referrals. Information was given out over the phone or mailed. With the implementation of the Comprehensive Services Act, PACCT has been handling an increased number of calls for information concerning the act.

PACCT referred many families to PACCT support groups, to support groups for Attention Deficit Hyperactivity Disorder (ADHD), and to Parents Anonymous. Two families were referred to the City of Richmond Community Mental Health Center and to that organization's crisis intervention unit. Callers also asked for information about child therapists and residential care facilities. Three families were referred to the Department for Rights of Virginians with Disabilities and two families were referred to the University of Richmond's Youth Advocacy Program. Fewer families were referred to local support groups at that point. Many family members felt that the support and affirmation they receive when they called the office helped tremendously and that groups were often difficult to attend.

Objective 5: *An implementation strategy to strengthen the network of parents and parent organizations by increasing formal and informal contacts among groups and individuals.*

PACCT has experienced a growth in number of parent support groups. This growth has been due, in part, to the Casey Foundation Initiative. PACCT staff were active in recruiting leaders who wanted to begin a parent support group to address their particular needs and the needs of the community. PACCT gave technical assistance, provided seed dollars in the form of mini-grants, and helped the groups get started.

During the third project year, the PACCT group in Warrenton held a workshop with Karl Dennis and an interagency team from Norfolk. Eighteen parents and several professionals attended the workshop. Five group leaders attended the Federation of Families meeting in Arlington. Two of the leaders were joined by their spouses at that meeting. Two couples who were preparing to begin new groups attended.

PACCT established a sibling group during the 1992-93 year. Parents and children came together; parents attended a support group meeting while children attended the sibling group. The leaders were very skilled and the children loved the group. One child said, "They should have this everyday for maybe four or five hours." The group let the children explore and share feelings and experiences, as well as affirm themselves and their relationships with their families. On the last evening, they invited their brothers, sisters, and parents to a pizza party.

One of the PACCT parent support group had two speakers address the issue of sexual abuse. Foster parents were able to share their concerns and experiences in dealing with this issue. A question-and-answer forum followed the main address. Another group met and discussed ways to increase their numbers, as well as strategies to deal with issues unique to their support group. One support group sent a parent to a mental health conference in April 1993. Many groups were in the process of re-organizing.

Objective 6: *A clearly articulated approach to providing technical assistance and support to newly forming or ongoing parent support groups, including "state-of-the-art" information on services for emotional disorders in children and adolescents, and the range of community based service options required to meet their needs.*

The PACCT project director met with several parent groups throughout the third project year. Visits were made to a group in Roanoke and one in Big Stone Gap. Staff also met with the leaders of a group in Henrico County and from Carver Annex Elementary School in Richmond. New support groups were developed in different areas across the state. Staff provided technical assistance to many of these developing groups. Feedback from family members and professionals indicated that the information was helpful. Further, staff sent out a letter of introduction and a survey sheet to all of the support groups requesting feedback on the types of resources and support needed. The results indicated that group leaders needed information on methods and strategies to revitalize groups. There were a number of respondents who requested information and assistance on starting new support groups.

Objective 7: *A system for ensuring timely provision of information on pending legislation, state planning processes, opportunity for providing public comment or public testimony at various administrative or legislative hearings relevant to improving services for children and adolescents with serious emotional disorders and their families.*

The primary legislative action during the third project year focused on getting the Comprehensive Services Act for Youth and Families (CSA) passed. This legislation provides mandatory parent involvement on interagency teams that plan care for children, with a focus on community-based, family-centered treatment. The act requires pooled funds from the child-serving agencies to increase options of services for children. The Governor, Secretary of Health and Human Resources, and agency heads all supported the legislation. Staff mailed a legislative alert to parents, volunteers, board members, and group leaders. They also encouraged telephone calls to legislators to support full funding for this program.

PACCT staff were invited as family representatives to give their insight and perspective on state and federal mental health policies. Carol Obrochta served on Virginians for Mental Health Equity. Carol Obrochta and Marisa Brown, project staff, were both invited to attend a committee meeting in Washington, D.C. to provide comments on mental health coverage in health care reform.

PACCT staff, parents, and volunteers gave feedback about the proposed Special Education Regulation changes. PACCT concerns focused on the proposed changes in terminology and wording, improper or vague definition of "professional," and the providers of services needed by some special education students. The proposed deletion of parental consent or knowledge was met with strong opposition. The Special Education Regulation committees agreed to rewrite the proposed changes in the regulations.

Objective 8: *A plan to expand and develop the network across the State to include: a) ongoing Board development and leadership expansion, including regular meetings, evidence of study and decision making structure such as subcommittees, management and oversight training. Board membership and Network Members must be comprised of no less than 51% family members of children or adolescents with serious emotional or mental disorders; b) strengthening of the financial and legal independence of Network Members, including a strategy for revenue development, and timelines and specific attention to organization's legal status. If Network Members including the contractor are not incorporated, a plan and a timeline to incorporate and obtain tax -exempt status within the period of the contract award; and c) a description of the policies that address the privacy of personally identifiable data.*

The PACCT board had 85% of its members as parents of children with emotional and behavior problems. Their children ranged in age from 10 to 22 years. New members were identified and joined the organization at the April 1993 meeting. (One new member was a father who worked at a court services unit in Petersburg; another was an education specialist from Northern Virginia.)

Board meetings were held every-other-month. Board development materials were ordered and available in the resource center. Board development issues were discussed but no training sessions were held. The three subcommittees (education, CSA, and funding) held meetings throughout the year.

WISCONSIN

Wisconsin Family Ties

Background

Wisconsin Family Ties (WFT) is a private, non-profit organization. WFT began in 1987 with the goal of providing support, information, and advocacy to families of children with serious emotional disabilities. In 1988, WFT was one of five states awarded a demonstration grant from NIMH which allowed them the opportunity to expand their services to families as a statewide organization. The WFT office is located in Madison and is staffed by a part-time executive director, Maggie Mezera, a full-time family advocate, and Sleri Mahotfey a part-time student intern. WFT's board of directors meets six times a year and consists of nine people, eight of whom are parents of children with serious emotional difficulties. Following is a summary of WFT activities during the third project year.

Objective 1: *A mechanism for providing inexpensive two-way communication with identified groups and others requesting services.*

WFT had a toll-free phone line since they opened their office in 1988. Initially they used a pooled toll-free number through the University of Wisconsin in Madison, but later moved to an independent line. The new line was partially funded through Mental Health Block Grant money and a federal "System Improvement Grant." In the final year, funding for the toll-free line was also partially provided by WFT's Post Adoption Support Network grant, their Dane County Project FIND grant, and funds from a CASSP contract which they had from the state.

The toll-free number was published in WFT's newsletter, *Family Ties*, and a WFT brochure. When families called WFT, they reached either the executive director, the family advocate, or an answering machine. Either the Family Advocate or the executive director returned the latter calls as soon as possible. Most of the calls requested information or referrals. There was a large increase in calls to WFT over the course of the contract. Calls increased from 867 for the second year of the grant to 2016 in the third year of the grant.

Objective 2: *A strategy to identify and engage underserved populations such as families from diverse cultural and ethnic backgrounds.*

Under the WINGS project, WFT worked with a family support outreach coordinator to assist in the development of support groups on Native American Indian reservations. The coordinator helped WFT plan a location for the WFT spring workshop that was accessible to as many of the tribes as possible. The one-day workshop was held at the Lac Courte Oreilles Ojibwa Community College, which is on the Lac Courte Oreilles

Indian Reservation in northern Wisconsin. Registration flyers were distributed to 225 families living on the 11 reservations in northern Wisconsin. Many Native American parents attended and 16 scholarships were provided. WFT also participated in a campout sponsored by WINGS in north central Wisconsin for Native American families who had children with disabilities.

Contacts with African-American families living in Dane County increased because of WFT's work with families receiving services from the Robert Wood Johnson Project FIND. To address needs of Milwaukee inner city families, WFT worked through a well-established Families Anonymous group. WFT also collaborated with the state in developing a grant application in response to the need for WFT to have a stronger presence in Milwaukee inner city as part of the state's proposed federal Child Mental Health Services Initiative. The application contained support for opening a WFT satellite office in Milwaukee and extending its services to families in that community.

WFT continued to provide scholarship funds to families to attend trainings. WFT partially or totally funded 29 parents to participate eight conferences sponsored by other organizations and 31 parents to attend two WFT sponsored conferences.

Objective 3: *A method to identify local parent/family controlled organizations, to foster network activities among these local organizations, and to obtain information on activities of these organizations.*

WFT continued to refer families to a variety of family-controlled organizations, including CHADD, the Parent Education Project (Wisconsin's PTI organization), First STEP (a statewide information and referral service), MUMS (a parent-to-parent organization for parents of a child with any disability, disorder, chromosome abnormality, or health condition), HUGS (a Dane county-based organization for youth alcohol and drug abuse problems), and Parents Anonymous chapters.

WFT was part of a group of about 100 parents of children with a wide range of disabilities who met to establish the structure and mission of a new organization, the Statewide Parent Empowerment Coalition, funded by the Wisconsin Council on Developmental Disabilities. A WFT parent was a speaker and workshop leader.

The three statewide mental health grassroots advocacy organizations in Wisconsin, WFT, AMI of Wisconsin, and the Wisconsin Network of Mental Health Consumers, jointly planned and sponsored a statewide leadership conference. Twenty WFT members attended the conference, which included a presentation describing existing joint family/consumer projects, a strategy session led by a community organizer, and action sessions organized by geographical location. In addition, three WFT families met twice with a newly formed group that focused on problems with the special education system in Wisconsin.

Objective 4: *A system of referring family members to existing family groups or to individual family members in their geographic area and for directing parents to existing agencies with the ability to answer questions and make referrals within the service delivery system.*

Requests for information and referrals continued to increase steadily over the year, doubling from the first quarter of the year to the last. The WFT family advocate, who had been providing information and referral only for Dane County families, was hired full-time and began work with families statewide. WFT publicized the ABC for Health Project, describing how to contact the health benefits counselors, who are parents with special training. WFT has referred many families served by Project FIND in Dane County to the WFT Dane County Support Group.

Objective 5: *An implementation strategy to strengthen the network of parents and parent organizations by increasing formal and informal contacts among groups and individuals.*

Parents and staff continue to attend and present at a number of statewide and national meetings. These include the annual statewide Children Come First Conference, the Parent Empowerment Coalition, the annual meeting of the Wisconsin Association for Children with Behavior Disorders, the national CHADD Conference, Collaborative Interagency Finance Workshop in New Orleans (where the Executive Director served as part of the faculty), the Robert Wood Johnson Mental Health Services Program for Youth annual meeting, two conferences in Florida, and a statewide conference on learning disabilities.

WFT continued to approximately 4,000 names, publish their newsletter, *Family Ties*. The WFT newsletter mailing list grew to approximately 4,000 names, adding more than 300 names in 1992-93: Most of the additions were family members.

WFT sponsored trainings including two trainings for professionals coordinating the newly funded county Integrated Service Programs, a WFT regional workshop, and a "parent ally" training for three newly hired parents who were serving as consultants in the Post Adoptive Support Network Project. The Post Adoptive Support Project (funded by a contract with the Wisconsin Department of Health and Social Services) was well-established. The purpose of this project was to provide ongoing peer support for adoptive parents of children with emotional disabilities in a 12-county area in the southwest part of the state. Parent "allies" were recruited and trained, and were paid as consultants by WFT, working up to 15 hours each month. They were matched with adoptive parents, providing one-to-one support and helping parents connect with existing support groups and other services.

Objective 6: *A clearly articulated approach to providing technical assistance and support to newly forming or ongoing parent support groups, including "state-of-the-art" information on services for emotional disorders in children and adolescents, and the range of community based service options required to meet their needs.*

WFT staff continued to offer technical assistance to support groups including resource packets, mailings to affiliate groups, small grants to cover some operating expenses to groups that request them, and staff attendance at support group meetings. WFT encouraged the support groups to apply for family and consumer self-help and peer support funds, that were available because of an increase in Wisconsin's Community Mental Health Block grant.

The Marshfield support group stopped meeting due largely to the availability of a strong CHADD group in the local area, to which WFT began referring families. Two new support groups were established in Waushara County and in Dodge County. A cross-disability group in Fond du Lac expressed interest in affiliating with WFT and will probably do so. WFT's CASSP funding provided for WFT attendance at meetings of the county Integrated Services Program directors to establish a working relationship with the staff of these programs, and ultimately with the families who receive services.

Objective 7: *A system for ensuring timely provision of information on pending legislation, state planning processes, opportunity for providing public comment or public testimony at various administrative or legislative hearings relevant to improving services for children and adolescents with serious emotional disorders and their families.*

A major thrust involved the "Children Come First" legislation, which included four related proposals. One of these proposals became law in 1989 and initiated the development of the county Integrated Services Programs. WFT participated in strategy meetings regarding submitting the three remaining proposals to the legislature, and was instrumental in developing one of the remaining three as "The Children's Mental Health Services Act."

At the same time, WFT monitored existing county Integrated Services Program initiatives that were shaping the children's mental health delivery system in Wisconsin. WFT was very involved in Project FIND, the RWJ program in Dane County, which served as a model and will probably become part of the plan for the way mental health services will be delivered statewide. Staff spent a great deal of time organizing and meeting with a group that defined the role parents will play in the delivery system developed in Dane County, and participated in two committees regarding the establishment of a managed care entity in Dane County. WFT parents participated in other Project FIND work groups, testified at a Dane County budget hearing regarding the need for respite services for parents not participating in Project FIND, and made calls to the Director of Dane County Human Services to support funding for children's mental health services. A focus group of ten WFT parents met with staff of both the Wisconsin Council on

Children and Families and Children Come First, Inc. (the managed care entity) to discuss what a mental health system for children should look like in Dane County after the RWJ Project ends in August 1994. A WFT parent was appointed to the Children Come First, Inc. board in 1993.

WFT attended and provided testimony at a statewide hearing regarding the establishment of funding priorities for the new federal Community Mental Health Block Grant monies coming into the state. One result of that testimony was a decision by the state to establish an request for proposals process based on a two-year cycle whereby family and consumer groups can apply for shares of $300,000 to fund their support and advocacy activities. They were also involved in meetings regarding Wisconsin's application for funding under the federal Child Mental Health Services Initiative sponsored by the Center for Mental Health Services

Other issues that WFT monitored include the proposed federal definition of children with serious emotional disturbance; a proposed administrative rule outlining an insurance benefits plan offered to small businesses in Wisconsin which had limited coverage for nervous and mental disorders; and bills containing provisions to assess families who have children in substitute care at the rate of 17% of their gross annual income to pay for the cuts of that care.

WFT informed parents of opportunities for training, including a local advocacy training in Dane County (130 announcements were mailed to parents in Dane County) and a leadership training cosponsored by WFT. WFT also did a statewide mailing about the new Parent Empowerment Coalition. The Wisconsin Protection & Advocacy (P&A) agency assisted in the formation of a new group of parents and advocates (including three WFT parents) that addressed educational issues. As part of that effort, WFT mailed 100 surveys statewide to parents who had difficulty getting special education services for their children. WFT was also active in the Wisconsin Difference Coalition in its legislative advocacy activities, with an emphasis in 1993 on programs for children. For example, WFT was involved in organizing and promoting parent participation in the "Don't Forget Our Children" state advocacy day sponsored by the coalition. WFT also organized parents to be involved in the "Support People Now" lobbying effort, which promoted the elimination of waiting lists for services.

Finally WFT continued to be involved in committee activities and advisory groups associated with children's mental health. They actively participated in an advisory group that monitored all of the child and adolescent programs at Mendota Mental Health Institute, one of two state mental health facilities. A WFT staff member participated in the P.L. 99-660 State Mental Health Plan Implementation reviews, and a WFT parent was nominated to fill a vacancy in Wisconsin's Mental Health Council.

Objective 8: *A plan to expand and develop the network across the State to include: a) ongoing Board development and leadership expansion, including regular meetings, evidence of study and decision making structure such as subcommittees, management and oversight training. Board membership and Network Members must be comprised of no less than 51% family members of children or adolescents with serious emotional or mental disorders; b) strengthening of the financial and legal independence of Network Members, including a strategy for revenue development, and timelines and specific attention to organization's legal status. If Network Members including the contractor are not incorporated, a plan and a timeline to incorporate and obtain tax -exempt status within the period of the contract award; and c) a description of the policies that address the privacy of personally identifiable data.*

During the fall, the board met monthly following a successful board training, then met bimonthly during the rest of the year. Four board members attended a training by John Carver entitled "Board Governance: A New Effective Model" and also viewed John Carver's videotapes at board meetings.

WFT engaged in several activities to strengthen their financial resources. They wrote a proposal for a Post Adoption Support Network Grant through the State Department of Health and Social Services, which was funded and provided them with an additional quarter-time staff. They signed a contract with Dane County to receive funding for their participation in Project FIND. This resulted in funding for a quarter-time family advocate until December, 1994. Staff met with the Director of the Bureau of Community Programs at Department of Health and Social Services to discuss the use of new Community Mental Health Service Block Grant funds for the fiscal year 1993. They proposed that $100,000 be designated for grants to consumer and family organizations for outreach activities, and followed up with a letter proposal and a budget for WFT's inclusion in that funding. This resulted in a two-year contract for WFT. They also negotiated and signed a contract with the State Department of Health and Social Services to perform activities under the CASSP grant. WFT applied for and received the federal Center for Mental Health Services grant to support statewide family organizations which began in October 1993.

SECTION III: QUALITATIVE ANALYSIS

The statewide family networks funded under this contract have experienced tremendous growth and challenges as articulated in each of the case studies in Section II. Section III provides a summary of the collective experiences of the fifteen statewide family networks between October 1992 and September 1993. This section brings together the experiences and challenges of the networks as well as the strengths, barriers, and issues family members addressed.

Objective 1: *A mechanism for providing inexpensive two-way communication with identified groups and others requesting services.*

Each of the statewide family advocacy organizations maintained a two-way communication system, with many using answering machines to ensure 24-hour coverage. These communication systems were available to and used by both parents and professionals. In almost all of the projects, calls from parents and professionals increased during the last project year. For example, in the state of Pennsylvania the number of telephone calls grew rapidly as the network attracted regional parent volunteers and sustained continuing relationships with the Mental Health Association as well as a strong alliance with state government. In Montana and Minnesota, family members worked very closely with the federally-funded Parent Training Institute resulting in large numbers of phone calls. The rise and fall in the number of telephone calls received from family members seemed to be influenced by the school year. Most projects reported that parent contact was lowest in the summer and increased in the fall when children returned to school programs. In general, telephone callers requested information regarding emotional and behavioral disorders, support during crises, referrals to services, and requests for contact with other parents and with support groups.

Most projects had access to a toll-free telephone line, often through sharing a line with another organization. In some cases, projects chose not to invest in a toll-free number. For example, Hawaii Families as Allies felt that the cost of such a line would be prohibitive given their budget and the number of long distance calls they received. Instead, the family organization chose to develop local networks of parents as a way of getting information and assistance distributed. This system of communication was challenged for a period of time when the regional coordinators on some of the neighbor islands were not available because of crises with their own children. In North Carolina, changes in the sponsoring organization's policy on working hours affected the access families had to the parent coordinator during evening and weekend hours. In the Nebraska project, poor health was a major factor that limited the availability of the parent coordinator. In other projects, high incidence of staff turnover created a barrier to the effectiveness of the communication system.

Objective 2: *A strategy to identify and engage underserved populations such as families from diverse cultural and ethnic backgrounds.*

All of the statewide family advocacy networks worked diligently to expand their strategies for involving family members from ethnically and culturally diverse backgrounds. Many offered scholarships or small stipends as methods to pay for fees, materials, meals, and travel expenses to attract the participation of family members who represent underserved populations. Projects in Georgia, North Carolina, Pennsylvania, Hawaii, Kansas, Virginia, and New Jersey tried strategies such as board appointments, part-time employment, and linkages to community leaders to include African-American families and professionals. Similar approaches were used by statewide family networks in Texas, Wisconsin, Vermont, New Mexico, Minnesota, Kansas, Montana, and Georgia to involve family members and professionals from the Native-American communities. Projects in New Mexico, Texas, North Carolina, Mississippi, and Georgia made special outreach efforts to family members and professionals from the Hispanic communities with particular emphasis on producing project literature in Spanish.

Objective 3: *A method to identify local parent/family controlled organizations, to foster network activities among these local organizations, and to obtain information on activities of these organizations.*

All of the statewide family networks described processes by which they identified existing support group meetings and made that information available throughout the state. Most projects also developed ways to identify and foster other kinds of networking activities among individual parents, advocacy groups, and professionals. For example, the project in Nebraska worked with the state referral and resource system to facilitate communication and resource sharing. The project in North Carolina developed a computer program which allows staff to link the family member or professional caller to resources available in their local area. In Hawaii, the cost of inter-island travel prohibited regular meetings, even on a monthly basis. Overall, annual conferences and workshops were employed to share information and foster network development activities in all of the statewide family networks.

Each of the project coordinators maintained contact with local and statewide parent organizations with which they collaborated and met on a regular basis. Most of the projects set up a system of regional coordinators or local parent contact persons who tracked and maintained information on the activities in their area. Most of the projects worked closely with the Parent Training Institute for their state to disseminate information and provide parent-to-parent arrangements for families of children with different disabilities.

Objective 4: *A system of referring family members to existing family groups or to individual family members in their geographic area and for directing parents to existing agencies with the ability to answer questions and make referrals within the service delivery system.*

Each statewide family network maintained a system for referring family members to other parents and to services. The projects in Texas, Pennsylvania, Mississippi, Georgia, and Hawaii depended to some extent on regional coordinators to make these referrals because of the sheer enormity of the amount of information necessary to make appropriate referrals in each part of the state. Each of the networks indicated that, based on a preliminary discussion with family members or professional callers, they were able to link the caller with resources although the availability of appropriate services were often limited. Most of the project maintained communication and exchanged information with school districts, community mental health centers, psychiatric hospitals, and residential facilities. Each of the networks had some direct relationship with one or more national advocacy organization such as the Alliance for the Mentally Ill, the Federation of Families for Children's Mental Health, and the Mental Health Association.

Objective 5: *An implementation strategy to strengthen the network of parents and parent organizations by increasing formal and informal contacts among groups and individuals.*

The statewide family networks described a wide variety of activities related to bringing together individuals and organizations interested in children with serious emotional disorders and their families. Most of the networks were involved in sponsoring or co-sponsoring state or regional conferences or workshops. In Vermont, Montana, Mississippi, Georgia, North Carolina, Pennsylvania, Minnesota, Wisconsin, New Mexico, Hawaii, Texas, and Virginia, an annual conference format was used to bring together family members and professionals. This particular strategy was a cost-effective way for several organizations interested in children's mental health to pool money and defray the cost of scholarships and travel for parents from across the state. Some projects opted for regional meetings as a way of bringing together family members and professionals from local areas.

Many of the statewide family networks sent representatives to the annual meeting of the Federation of Families for Children's Mental Health and some participated in the Alliance of the Mentally Ill annual conference. All reported that these experiences allowed for sharing of techniques across state boundaries. For example, Georgia Parents Support Network participated in regional planning and development meetings with family members in Alabama and South Carolina. The parent coordinator and the director of the Mental Health Association in Hawaii helped parent leaders in North Carolina strengthen their relationship with their sponsoring organization by sharing experiences and problem-solving methods. Parent coordinators routinely refered individual families to their counterparts in other states.

Objective 6: *A clearly articulated approach to providing technical assistance and support to newly forming or ongoing parent support groups, including "state-of-the-art" information on services for emotional disorders in children and adolescents, and the range of community based service options required to meet their needs.*

All of the statewide family advocacy networks developed or had access to written materials focused on forming or maintaining support groups. Many also provided regular workshops or training sessions for support group leaders. This approach was used in Pennsylvania, Georgia, Hawaii, North Carolina, Montana, Wisconsin, Vermont, Minnesota, New Mexico, Virginia, and Kansas. Some networks made an extensive library of books, articles, tapes, brochures, and printed literature available to parent leaders. On-site technical assistance was provided by parent coordinators in most of the networks when new groups were forming. Existing groups received technical assistance in a number of ways. Parent coordinators may have visited groups periodically, providing regular information sheets and legislative updates, as well as information about training through other groups.

Objective 7: *A system for ensuring timely provision of information on pending legislation, state planning processes, opportunity for providing public comment or public testimony at various administrative or legislative hearings relevant to improving services for children and adolescents with serious emotional disorders and their families.*

All of the statewide family networks had some system for sharing legislative information with parents which usually included mailed legislative alerts and telephone trees. Further, most networks had some system for training parents who wanted to participate at the policy level. This often included workshops or articles on topics such as giving testimony, and special training sessions at conferences. Further, all of the statewide family networks had family members who participated in policy making committees such as legislative task forces or state planning councils. Although the amount of influences varied by project, all were involved in some way in the planning, implementing, or evaluating of policy change initiatives related to children's mental health.

Objective 8: *A plan to expand and develop the network across the State to include: a) ongoing Board development and leadership expansion, including regular meetings, evidence of study and decision making structure such as subcommittees, management and oversight training. Board membership and Network Members must be comprised of no less than 51% family members of children or adolescents with serious emotional or mental disorders; b) strengthening of the financial and legal independence of Network Members, including a strategy for revenue development, and timelines and specific attention to organization's legal status. If Network Members including the contractor are not incorporated, a plan and a timeline to incorporate and obtain tax -exempt status within the period of the contract award; and c) a description of the policies that address the privacy of personally identifiable data.*

Each of the statewide family networks engaged in some activities related to board or advisory group training. In some cases, training was developed for an entire board. In other projects, individual board or advisory group members were sent to a conference or workshop on board development. In almost all of the statewide family networks, the governing body reported plans to raise additional funds by writing grants and proposals, although few had a formal resource development plan. The boards of directors associated with projects in Kansas and Nebraska were involved in hiring new executive directors and changing day-to-day operating procedures. In Hawaii, Vermont, Mississippi, and Pennsylvania, the boards were involved in strategic and long range planning processes.

Most of the projects had established boards or advisory committees. In most cases, these bodies met on a monthly or quarterly basis. All projects reported that the recruitment of family members to serve on the governing board was an ongoing challenge. Projects in Hawaii, Vermont, Minnesota, Montana, and Nebraska were either in the process of, or had recently received, their nonprofit tax exempt status. By the end of the third project year, 13 of the 15 statewide family networks were either independent or in the process of securing independent tax exempt status. Two of the networks, those in North Carolina and Texas, chose to remain projects of their sponsoring organization.

SECTION IV: QUANTITATIVE RESULTS

Family members who manage statewide advocacy networks are particularly in need of the information that can be obtained from ongoing program evaluations. Because most of the projects funded were in the beginning stages of building organizational capacity, the evaluation was purposely designed to maximize the utility of the information for the individual project. To this end, activities that would build data collection and information utilization capacity within the family networks were emphasized.

The following pages provide an empirical analysis of a selected number of variables collected by statewide family advocacy organizations. This empirical description does not represent all of the data collected by the networks. As a part of their contract, each family network agreed to keep records that documented their progress in achieving project objectives. The specific data elements chosen as evaluation indicators for each objective varied because projects were given the opportunity to select their own data elements and encouraged to chose those items that would be most useful to them in managing their organization and documenting the outcomes of their unique efforts. While this approach maximized each project's involvement in the evaluation and the ultimate utility of the data for each project, the resulting information was difficult to summarize and should not be used to compare projects with each other.

Some data elements were collected by a number of statewide organizations. For example, the number of incoming calls from parents, the number of incoming calls from professionals, and the number of families on the statewide family organization's mailing lists, were common data elements collected by the majority of the projects. These data elements are discussed in this section and are presented in table form in the Appendix.

The tables in the Appendix include entries for quarters one, five, and nine. These quarters represent the first quarters of years one, two and three of the federal contract. Quarter one represents the period of October 1990 through December 1990; quarter six represents the period of October 1991 through December 1991 and quarter 10 represents the period of October 1992 to December 1992. Data from quarter twelve (the last quarter of the contract) was not included because projects were not required to submit a report at the end of that quarter and many chose not to. In some cases, data from quarter eight is used rather than quarter nine. At the beginning of the third project year, the objectives used to guide the evaluation were modified and projects were allowed to revise their data collection system. Therefore, in quarter nine the majority of projects changed data collection procedures and definitions.

Many of the data elements were tracked by fewer than half of the states, just a few states, or even a single state. In some cases, data elements were given the same label but measured in different ways by different projects. Missing information simply means that a particular statewide family advocacy organization did not collect the information in that format for that quarter. Caution must be taken to avoid using the data comparatively. The data should be viewed as a description of some of the activities within family advocacy networks that lend themselves to numerical coding.

Objective 1: *A mechanism for providing inexpensive two-way communication with identified groups and others requesting services.*

Number of incoming calls from parents/or caregivers (see Table 1). Calls received from parents increased considerably between the first quarter of the 1990-1991 federal fiscal year, and the first quarter of the 1992-1993 federal fiscal year. Overall, the frequency of calls from parents doubled between the first and fifth quarters, and tripled between quarter one and quarter nine.

Calls received from parents in statewide family advocacy organizations in Texas and North Carolina increased between quarters one and five and then declined in quarter nine. The decline in calls from parents in North Carolina may be attributed to the resignation of the parent coordinator. In this particular organization, calls from families were received by the parent coordinator and hotline staff person. The resignation of the parent coordinator created a decrease in access for many families during weekend and evening hours. The decrease in calls in the Texas statewide family advocacy organizations is probably explained by a number of factors. The most likely explanation involves a change in the way calls to the toll-free number were counted. Only calls addressed specifically to the parent coordinator of the TX-NET project were included in the total number of calls reported during the third federal fiscal year. Prior to that, calls received by other staff were also counted.

Number of incoming calls from professionals (see Table 2). The distribution of calls from professionals was similar to the pattern of calls received from parents. In general, the number of calls from professionals increased across time. In some states, the number of calls from professionals doubled between quarters one and five, and more than tripled between quarters one and nine. Exceptions noted were in the distribution of calls from professionals in statewide projects located in Georgia and North Carolina. Calls received from professionals in Georgia declined after the first quarter. Project staff spent many hours attending meetings, facilitating support networks, and providing individual case advocacy services. In North Carolina, calls from professionals initially increased in quarter five then decreased considerably in quarter nine. Change in executive leadership of the sponsoring organization created changes in the work hours of the parent coordinator. Calls handled by the coordinator during the evening and weekends were prohibited.

Number of families on mailing list (see Table 3). Data regarding the number of families listed on the mailing lists of statewide family advocacy organizations were available for eleven projects. The number of names on the mailing lists ranged from 108 to 3,238 during quarter 1 to a range of 175 to 5,324 entries in quarter eight. Parent coordinators in statewide family advocacy organizations in Minnesota, Montana, and Pennsylvania had understandably larger mailing lists than some of the newer projects. For example, by the end of the eighth quarter, the Parents Involved Network in Pennsylvania reported almost 2,150 families on their mailing list; in Montana more than 2,800 families were included on their mailing list; and in Minnesota more than 5,300 families were identified on the mailing lists. The projects located in Minnesota and Montana were under the umbrella of parent training institutes and this relationship with a much larger parent organization may have enhanced the capacity to reach more families.

Objective 2: *A strategy to identify and engage underserved populations such as families from diverse cultural and ethnic backgrounds.*

Most of the data elements reported by statewide family advocacy organizations on this objective were unique to each project. This reflects the individual conditions in each state and unique approaches used by each project. The number of contacts with minority community leaders and outreach contacts made to underserved populations were tracked by some of the organizations. However, the numbers reported for each of these data elements were based on different units of measurement such as personal contacts, presentations, telephone calls, referrals, mailings, or some combination of those methods. The variation in methods of measurement used made it difficult to arrive at summary statistics or compare data across projects.

Twelve statewide family advocacy organizations reported contacts to underserved populations. This does not mean that the remaining statewide projects did not make such contacts; however, it does mean that they did not chose to document this activity. Seven statewide projects, including two that did not report on making contacts to underserved populations, reported making contacts with minority community leaders. Four statewide family advocacy organizations reported having workshops for persons from diverse cultural or ethnic backgrounds, and two statewide organizations reported having workshops for professionals with diverse backgrounds. A number of additional activities tracked included distributing public service announcements to radio stations with listening audiences from predominantly ethnically diverse communities, developing educational materials specifically for families from ethnically and culturally diverse backgrounds, and providing scholarships for families from culturally and ethnically diverse backgrounds to defray costs for attending workshops, conferences, and other educational forums and events.

Objective 3: *A method to identify local parent/family controlled organizations, to foster network activities among these local organizations, and to obtain information on activities of these organizations.*

The number of active support groups were tracked by eleven statewide family advocacy organizations (Table 4). The average number of groups did increase between quarter one and quarter nine. The rate of creating new support groups showed slow upward growth between quarters one and five. The number of active support groups tended to grow in quarter one and quarter five and then level off. There was a decline in the number of active groups reported for most of the projects in quarter nine. Only two to three projects showed a steady upward trend.

A number of factors need to be considered about the nature and life cycle of support groups. A support group may start, continue for several months, then end due to declining attendance. The change in parent leadership may also adversely affect the maintenance of support groups. Further, parent leaders and members of support groups may move, may burn out, may no longer need the support group, or their child may age out of the system. Maintaining parent attendance is a difficult and challenging issue for support group leaders. The lack of child care, personal crises, and other competing demands contribute to the fluctuation in parent attendance. Clearly, support groups among the fifteen statewide organizations have experienced similar patterns of development. They have existed for a period of time, experienced declines in parent attendance, and have been replaced by new groups.

Given the nature and life cycle of support groups, an enormous amount of energy, resources, and time commitments by family members are used to initiate and maintain support groups. Generally speaking, many of the statewide family advocacy organizations redefined this part of their mission to focus on providing support networks rather than continuing to develop support groups. This shift in emphasis provided the flexibility necessary to allow individual family members to provide support to one another. This cost effective method of providing support may have taken place on the telephone, during chance meetings and accommodated the time demands of individual families.

Collaborative meetings, workshops, or training sessions with other organizations; joint activities, advertising, or listing other parent networks in their newsletters; articles written by parents, referrals, and linkages to other organizations; membership in other organizations; and information sharing were also mentioned as data tracked by statewide family advocacy organizations to identify local family-controlled organizations and to foster networking activities.

Objective 4: *A system of referring family members to existing family groups or to individual family members in their geographical and for directing parents to existing agencies with the ability to answer questions and make referrals within the service delivery system.*

Referrals to support groups. In general, referrals to support groups increased between the first and second contract years, although the number of referrals tended to go down in most projects during quarter eight. The reduction may ben due to the seasonal effect of the summer months. Referrals to support groups increased by two-thirds, and referrals to family members almost doubled between quarter one and quarter eight. This pattern was not consistent across statewide family advocacy organizations, with referrals to support groups decreasing in four statewide projects during that time.

Referrals to family members. Referrals to family members increased between quarter one and quarter five, showing a general pattern of steady growth. Five statewide family networks showed continued growth between quarter five and quarter eight. The rate of referrals to family members leveled off by quarter eight for most projects. Summer vacations and related activities may have influenced the availability of family members to reach out to each other. The leveling off may also reflect reaching the full capacity of project staff and volunteers to make and accept such referrals.

Referrals to service providers. Between quarters one and five, requests for referrals to service providers increased by more than two-and-a-half times. Referrals to service providers ranged from 1 to 117 in quarter one and from 3 to 415 in quarter five. This increased variation is most likely an indication of the advanced developmental level of the organizations and the capacity of project coordinators to respond to requests for information. The pattern of referrals to service providers varied across projects between quarters five and nine.

Objective 5: *An implementation strategy to strengthen the network of parents and parent organizations by increasing formal and informal contacts among groups and individuals.*

There were no data elements reported by a sufficient number of statewide advocacy organizations to warrant analysis. Projects used a variety of strategies to achieve this objective and chose to track a variety of data elements. For example, family members reported that they held training sessions or workshops, provided scholarships to parents to attend workshops, and provided mini-grants to support groups or networks.

Objective 6: *A clearly articulated approach to providing technical assistance and support to newly forming or ongoing parent support groups, including "state-of-the art" information on services for emotional disorders in children and adolescents, and the range of community-based service options required to meet their needs.*

Attending a support group to provide technical assistance was one strategy for which data were available for thirteen projects. Use of this strategy depended on the project coordinator's available time. Family members reported data on a number of other approaches used to provide technical assistance to support groups such as providing mini-grants, books, and other resource materials, assisting new groups in getting started, technical and emotional support to group facilitators, and in-person contact and technical assistance during support group meetings. The number of visits to support groups declined, as expected, over time as support groups were established. During quarters one and five, the parent coordinator may have visited some groups multiple times.

Objective 7: *A system for ensuring timely provision of information on pending legislation, state planning processes, opportunity for providing public comment or public testimony at various administrative or legislative hearings relevant to improving services for children and adolescents with serious emotional disorders and their families.*

Family members in ten statewide projects reported data on mailing legislative alerts, maintaining an active telephone tree, and making telephone calls about legislative issues as strategies used to fulfill this objective. Family members reported data on a variety of other approaches to this objective, including the incidence of parent testimony in ten projects, family members in eight statewide projects serving on boards or committees in eight projects, and training on legislative issues in five projects. Additionally, a number of family members in statewide projects documented activities such as telephone calls to legislators and writing articles to address legislative issues.

Objective 8: *A plan to expand and develop the network across the State to include: a) ongoing Board development and leadership expansion, including regular meetings, evidence of study and decision making structure such as subcommittees, management and oversight training. Board membership and network members must be comprised of no less than 51% family members of children or adolescents with serious emotional or mental disorders; b) strengthening of the financial and legal independence of Network Members, including a strategy for revenue development, and timelines and specific attention to organization's legal status. If network Members including the contractor are not incorporated, a plan and a time frame to incorporate and obtain tax-exempt status within the period of the contract award; and c) a description of the policies that address the privacy of personally identified data.*

Data related to this objective are not provided in table form because this objective was added at the beginning of the third project year. The number of board meetings or the number of members attending board meetings were often selected for documentation. Other potential indicators related to this objective included incidence of board development training, numbers of board members attending training outside of the organization, and grant writing or other forms of fundraising activities. Additional infrastructure development activities reported by family members included developing subcommittees, attending committee meetings, and participating in work groups.

SECTION V: FUTURE DIRECTIONS AND CONCLUSIONS

The foregoing chapters examined the progress of statewide family advocacy organizations on eight project objectives between September 1990 and September 1993, three federal fiscal years. Based on this information, the authors concluded that statewide family organizing remains a promising strategy for promoting family support and system change in children's mental health.

Solutions to the challenges of reaching out to ethnically and culturally diverse families, increasing financial resources, effectively utilizing lawsuits to change ineffective and outdated policies, programs and services, and furthering the infrastructure development of family advocacy organizations will not be accomplished universally for family-controlled projects through one particular strategy. Although family members of children with serious emotional or behavioral disorders share a common vision and desired outcomes--a better service delivery system--they will need to continue to develop and share strategies that help organizations plan, implement, and evaluate their activities. The following discussion highlights challenges that concerned statewide family advocacy organizations at the end of the 1992-1993 fiscal year and guided their future plans.

Georgia: Georgia Parent Support Network plans to accomplish eight tasks in the future:

1. *Increase staff hours so that outreach can be expanded.* Additional staff hours will be used to reach out to families of children of serious emotional disorders in rural areas of the state. Further, additional resources will be used to increase the participation of more families from diverse backgrounds;
2. *Continue expansion of support groups.* The Network seeks to increase the number of support groups and parent contacts in all counties of the state;
3. *Support new projects that involve family members.* The Network seeks to secure funds to defray the costs of sponsoring fun, recreational, and respite programs for families of children with serious emotional and behavioral disorders;
4. *Expand collaboration with private organizations.* The Network seeks to expand its partnerships with community mental health centers and interested groups that promote advocacy, support, and system change in children's mental health;
5. *The network seeks to increase participation with all child-serving agencies* such as juvenile justice centers, family preservation programs, child welfare organizations;
6. *The network plans to obtain additional office space* to allow for evening and weekend activities sponsored by family members;
7. *The network plans to engage consumer organizations* such as Georgia Alliance for the Mentally Ill, Mental Health Association of Georgia, and other interested groups in designing and implementing joint support activities for families of children with serious emotional disorders; and

8. *The network will work to expand its business plan and look for additional funding* through foundations, corporations, private industry, and local, state, and federal public sources.

Hawaii: Hawaii Families As Allies (HFAA) is focused on improving policies, programs, and services in children's mental health by increasing training for and support to families of children with serious emotional and behavioral disorders. HFAA will continue to shape the planning and delivery of children's mental health services through participation in Child and Adolescent Mental Health Executive staff meetings. Through participation in weekly meetings, the Executive Director assists in strategic planning, reviewing program operations, and maintaining quality assurance. HFAA joined a number of organizations and families in a class action lawsuit. The lawsuit asked for federal support and administrative sanction in establishing and managing a comprehensive system of care with a range of programs and services that will meet the individual needs of families of children with serious emotional and behavioral disorders. This class action lawsuit included several families to whom HFAA has provided technical assistance and extensive support. Through this and other activities, HFAA is expected to play a large role in shaping new programs and services for families and children with emotional and behavioral disorders.

Kansas: Keys for Networking is pursuing a plan of development and leadership expansion. By the end of the 1992-93 fiscal year, three of the support groups had their own independent status and nine had their own names, an indicator of the growing leadership pool. Another major objective for Keys for Networking Inc. was in the areas of staffing and board development. The organization experienced substantial staff turnover in the past several years and worked to stabilize the organization's activities and increase board capacity. Improving collaboration between provider agencies was another objective Keys For Networking pursued on behalf of children with serious emotional and behavioral disorders.

Further, the organization received a number of requests to provide support to families of children with dual diagnosis. Children with a diagnosis of behavior disorder and mental retardation were referred for advocacy, information and referral, and parent support. These additional requests increased the workload of staff and posed a challenge to the organization's purpose of sustaining families. Another challenge to Keys for Networking was changing the manner in which families of children with serious emotional disorders are treated and viewed. Staff and board members spent a considerable amount of time redirecting the manner in which families are treated. Educating professionals about viewing the child and family from a strengths perspective continues to be a major objective of the organization for the future.

Minnesota: Project for Parents of Children With Emotional or Behavioral Disorders (EBD Project) aims to continue the provision of individual assistance and information to families of children with emotional or behavioral disorders. This support represents a critical need and will serve as a catalyst to family participation in system reform in Minnesota. The EBD Project plans to continue its efforts to increase the numbers of racially and culturally diverse family members involved in all project activities. Parents throughout Minnesota who received training to serve on policy committees regarding children's mental health services fulfilled a role that was facilitated, but not driven, by the EBD Project. A cadre of trained parents in key positions on local and state committees will have an enduring impact on the development of local services for children, and on the design of permanent policies at the state level in Minnesota's state-organized and county-implemented service system.

The Minnesota Association for Children's Mental Health (MACMH), developed by staff of the EBD Project, received a grant to provide small scholarships in the amount of $100 to $200 dollars to interested support groups to sustain or expand their development. PACER and MACMH plan to coordinate activities related to the expansion of a parent network in Minnesota and collaborate on initiatives designed to ensure that children with emotional or behavior disorders are served based on their needs, values, and unique circumstances. PACER and MACMH plan to continue providing complementary services for families of children with emotional or behavioral disorders. They will ensure continuation of the development of parents as advocates for their children and others, and for the creation of a statewide array of community-based services.

PACER plans tocontinue to provide ongoing technical assistance and support to parent support groups. These groups are expected to serve an important advocacy function as a voice promoting services at the community level for children and families. Finally, parent participation in the development, passage, and implementation of the Comprehensive Children's Mental Health Act, which mandates the creation of comprehensive community-based services for children and youth with emotional and behavioral disorders, is expected to change the service system in Minnesota. Whether parents will be able to garner enough strength in numbers to convince the state legislature of the critical need for full funding of the statewide services covered under the Act remains a major challenge.

Mississippi: Mississippi Families As Allies (MSFAA) will assist in policy development, planning, and oversight of the implementation of Senate Bill 2626. This landmark child mental health initiative mandates an interagency agreement to pool funds being used for out-of-state and inappropriate in-state residential treatment for children and adolescents with serious emotional disorders. These funds are to be used to create pilot comprehensive individualized systems of care using both traditional and non-categorical wraparound services. Local coalitions will form management entities to operate these pilot systems of care. Services will be delivered based on a plan of care developed by multi-disciplinary teams that include parents of children with serious emotional and behavioral disorders. MSFAA will provide family support and assistance to case managers assigned to local systems of care.

Montana: Parents Let's Unite for Kids (PLUK) and the Family Support Network (FSN) continue their efforts to expand the number of staff and volunteers so that they can serve more families. Project staff will continue to broaden the fiscal base of the organization. They also seek to serve more parents and educate more professionals about the value of parent expertise and participation. PLUK developed successful strategies for serving the Native American population. Plans were underway to hire a Native American individual living on a reservation to pilot a community-based, culturally-sensitive service. PLUK embarked upon a new project, the Family Liason Project, that supports families serving as case managers for their children. Project staff interacted with all state and local agencies to provide services for six families. Continued funding for this project is a priority.

As a result of parent testimony and other supports, funding that paid for hospitalization based on the child's income was reduced in favor of community-based services. The state of Montana now uses a managed care system based on the Massachusetts managed care model. Parents will continue to be actively involved in the development of services in their regions. It is hoped that changes in the first choice of services from inpatient hospitalization to community-based, in-home services will have a positive impact on children and families. PLUK and the FSN will continue to work on the development of appropriate mental health services within managed care.

Nebraska: Nebraska Family Network. The board and staff of the Nebraska Family Network plan to work to enhance the organization's infrastructure and terorganizational relationships. They hope to create a more efficient and effective working relationship between the staff and board of directors by revisiting policies and procedures to determine their current and future feasibility. Further, they plan to sponsor additional board development activities, solidify staff management procedures, and continue developing better avenues to provide support and advocacy for families of children with serious emotional disorders.

New Jersey: Statewide Parent Association for the Children's Effort (SPACE) seeks to obtain its independent tax-exempt status as well as to diversify its funding and resource support base. SPACE aspired to be a tax-exempt, nonprofit organization, but reported not having the cooperation of their sponsoring organization. As soon as the parent director can secure the necessary accounting documents from the sponsoring organization, the parent leaders of SPACE will complete the application process for independent status. The movement to independence will allow them to pursue small grants and foundation support through their own efforts. They plan to continue to provide parents with information and support through printed media, meetings, and case and legislative advocacy.

New Mexico: Parents for Behaviorally Different Children (PBDC) seeks to increase its funding base by writing proposals to hire more family and child advocates. They plan to add two additional employees to assist individual families with advocacy in areas such as school suspensions, individual education planning, discharge planning at mental health and correctional facilities, and education to professionals and service providers about parents' rights and responsibilities. PBDC will continue to assist case managers in influencing the special education process in favor of the unique needs and circumstances of families with behaviorally different children. PBDC will continue to work with state-run treatment centers for violent youth offenders to develop plans to assist families with transportation and lodging resources. These supports are needed so that families can remain active participants in their children's treatment. PBDC will continue to advocate for family liaison positions at state-run facilities to ensure better linkage and collaboration between families, professionals, and community resources. PBDC aims to assist in the development of prevention services for families so that they are provided the same supports offered to foster families. PBDC's vision is to exist until families are treated as equal partners, until children and youth with neurobiological, emotional, or behavioral differences are treated as individuals worthy of dignity and respect, and until family support services are considered core services in the children's mental health system of care.

North Carolina: North Carolina Alliance for the Mentally Ill-Child and Adolescent Network/ Federation of families for Children's Mental health (NC AMI-CAN/FFCMH) seeks to improve and expand the service delivery systems for families of children with serious emotional and behavioral disorders. Planning will continue to serve as a major tool to establish families as advocates for children with special needs. Because family input is viewed as an important component to shaping systems of care for children, NC AMI-CAN/FFCMH aims to promote alliances between parents and professionals in a number of ways. The Network plans to facilitate a direct dialogue between families and legislators about releasing funds for programs and services that are ready for program implementation. NC AMI-CAN/FFCMH also plans to strengthen its alliances with other advocacy networks such as Coalition 2001, a network comprised of family members, service providers, and advocacy organizations seeking to enhance children's mental health policies, programs, and services. Community education on the issues and training in advocacy will continue to be the thread that binds families from different regions of the state together.

Pennsylvania: Parents Involved Network of Pennsylvania (PIN of PA) embarked upon a plan to reach out to families of children with serious emotional disorders from a number of diverse cultural and ethnic backgrounds. They also plan to increase funding to pilot projects and test innovative model programs across different regions of the state. Additionally, they seek to enhance the infrastructure of the organization and continue to serve as a major support system to families, professionals, and community organizations and networks interested in promoting system improvements in children's mental health. To accomplish these goals, PIN of PA is continuing to undergo a strategic planning process that addresses each through a series of action-oriented steps, time frames, and anticipated outcomes.

Texas: Project TX-NET will continue to support the involvement of trained family members in developing proposals for increased funding and program development in children's mental health. Through its multi-disability focus, the organization will work on behalf of families of children with serious emotional disorders. The leaders of TX-NET will continue their collaborative efforts with other advocacy groups whose primary focus is on children with serious emotional disorders and statewide reform of family support and system of care development.

Vermont: Vermont Federation of Families for Children's Mental Health continues to face a number of challenges. Parent-to-parent contacts were established statewide; however, maintaining support groups in some areas was a challenge. The creation of local networks in the Lamoille and Rutland regions remains an organizational objective. The organization will continue to be a valuable resource to families through the Respite Care Project. This Project will continue to recruit and sustain as many unique and flexible respite arrangements for children and families as possible given available funds and personnel. Policymakers of the organization will continue to place greater emphasis on board leadership and development. As this organization grows, its focus on building board capacity is timely and pragmatic. Finally, creating a regular dialogue with the Abenaki Native American community is an ongoing objective.

Virginia: Parents and Children Coping Together (PACCT) will continue to advocate for appropriate assessment and early intervention programs and services. Through public education, PACCT will continue to disseminate information about children and youth with mental, emotional, and behavioral disorders, and their families. Additional staff will be needed to enable PACCT to achieve greater community impact and to reach "at risk" families and children. Building stronger alliances with service providers and other organizations with similar aims is another future objective of PACCT. This will be achieved through establishing collaboration between parents of children with special needs and provider agencies.

Wisconsin: Wisconsin Family Ties plans to continue their efforts to support families through informal and formal parent-to-parent contacts, support groups, and community networks. Wisconsin Family Ties will continue to develop new strategies to engage African American families in the organization. The organization used a number of statewide outreach activities such as providing information and referrals, resource materials, and scholarships to African American and Native American families of children with serious emotional and behavioral disorders. The organization plans to expand their activities and open a satellite office in the Milwaukee area.

Enhancing the infrastructure of Wisconsin Family Ties is another objective staff will continue to pursue in the future. The board seeks to clarify policies that address governance and strengthen relationships between board, staff, and families served by the organization. The staff is continuing to develop their capacity to reach and support as many families statewide as resources permit.

Summary and Implications

Statewide family advocacy organizations, through dedicated parent leadership, have made major advances during the three years of the CMHS contract. Their accomplishments and discoveries are important to the future developments of advocacy networks. The major areas of advancement, and also the major challenges, are summarized below.

Reaching out to underserved populations. Most of the statewide family organizations reported that they aggressively pursued new and different ways of increasing their outreach to persons from diverse backgrounds. Because this is an untested arena, projects had to develop new strategies and then try them out, resulting in uneven outcomes at times. Most of the organizations focused some efforts on actively recruiting board members and staff from diverse racial and cultural backgrounds to assist in the achievement of this objective. Some organizations pursued additional funding sources in order to mount a special program of minority outreach. This area continues to be complex and challenging for service providers as well as caregivers. Some of the ideas tried by these projects will prove useful to others who wish to develop support and advocacy services for parents of color.

Resource development. Family members in all statewide family advocacy organizations continue to work toward the development of a stable funding base for their organization. Most organizations sought support from foundations, corporations, and public agencies, as well as experimented with membership schemes and local fundraising events. The amount of effort and energy required for fundraising resulted in a drain on family member leadership and staff and constituted a major frustration for those involved. Continued preoccupation with fundraising detracts from the primary goals of these organizations: to support families and influence the service delivery system.

Family support. All of the statewide family networks described a number of strategic objectives and activities related to increased family support and advocacy. In general, family support, outreach, and advocacy strategies were well-conceptualized and becoming more sophisticated. Further, many projects were successful in developing unique strategies for family support and outreach that fit the characteristics of their states and individualized needs of subgroups within the states. The work of these family organizations made a substantial contribution to our understanding of how to provide support and information to families and how to make initial contacts.

System change. This report contains many examples of successful efforts to influence the system of care. These changes came through careful legislative work, lawsuits, and grievances, as well as persistent collaboration with service providers. Almost every state had at least one example of involvement in changing the service system to better meet the needs of families. The impact of the efforts toward system change extended by these 15 projects will only become clearer in future years.

Infrastructure development. The amount of emphasis on infrastructure development varied, depending on the developmental stage of the project at the time the funds were awarded. Some of the projects had been in existence for years and their focus tended to be on board training and leadership development. Other, newer projects, made major advances during the three years in recruiting and establishing an active board, opening an office, setting up communication procedures, and developing the capacity to deliver support and advocacy services. The maintenance of a viable grassroots organization is a continual process, one that was complicated by some turnover in family member leadership and supportive professionals.

The lessons learned from these fifteen statewide family networks will be helpful in the future development of research or evaluation technology for studying family networks. The very structure of these organizations, in addition to their extensive use of volunteers, complicated the process of collecting common data from each site. Involvement of family members in general in the research process and the involvement of the leadership of the statewide organization in specific are both worthy goals; one only partially accomplished in this evaluation. Continued efforts to involve family members and other caregivers in a fundamental way in the research process will undoubtably lead to creative solutions to some of the problems faced.

There are many unanswered questions about both the development and outcomes of family advocacy networks. Future studies of statewide family networks might fruitfully explore questions such as: (l) To what extent do services provided by family-run networks impact the lives of families of children with serious emotional or behavioral disorders?; (2) What impact do statewide family networks have on service delivery systems, legislation, and system change?; (3) How are statewide family networks supporting and involving people from culturally diverse backgrounds?; (4) What interorganizational relationships do statewide family networks develop and how do these relationships influence the outcome of the network activities?; and (5) What are the life cycle experiences of statewide family organizations as they develop over time? Although our current knowledge about the impact of family advocacy networks is limited, continued efforts to systematically examine both outcome and process should contribute to the children's mental health service system of the future.

SECTION VI: REFERENCES

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APPENDIX

Quantitative Results

Objective 1: *A mechanism for providing inexpensive two-way communication with identified groups and others requesting services.*

TABLE 1. Number of incoming calls: Parent/caregiver.

STATE:	Q1	Q5	Q9
Georgia	61	203	201
Hawaii	100	--[1]	219
Kansas	100	129	212
Mississippi	5	67	106
Minnesota	275	410	866
Montana	337	705	922[1]
Nebraska	58	232	354
New Mexico[2]	24	65	129
New Jersey	136	164	230
North Carolina	110	171	131
Pennsylvania	75	556	763
Texas	40	59	41
Vermont	12	63	192
Virginia	23	108	124
Wisconsin[3]	166	168	245

Note: Q=Quarter.

* Data from quarter 8. Data format from quarter 9 was not available in this format.

[1] Incoming and outgoing during second year were combined; therefore, number of incoming calls could not be reported.

[2] Local parent calls were estimated in first year.

[3] Toll-free telephone line calls were included in totals.

TABLE 2. Number of incoming calls: Professional.

STATE:	Q1	Q5	Q9
Georgia	96	53	59
Hawaii	62	--[1]	143
Kansas	5	187	304
Mississippi	0	98	72
Minnesota	137	102	163
Montana	64	222	160*
Nebraska	42	240	239
New Mexico	32	27	90
New Jersey	33	132	116
North Carolina	93	146	23
Pennsylvania	50	284	495
Texas	4	19	27*
Vermont	12	114	212
Virginia	14	92	112
Wisconsin[3]	88	70	104

Note: Q=Quarter.

[1] Incoming and outgoing during second year were combined; therefore, number of incoming calls could not be reported.

[2] Data from quarter 8. Data from quarter 9 was not available in this format.

[3] Toll-free phone line calls were included in totals.

TABLE 3. Number of families on mailing list.

STATE:	Q1	Q5	Q8
Georgia	176	593	602
Hawaii	108	135	175
Mississippi	128	209	
Minnesota	3238	4332	5324
Montana	2032	2408	2813
New Mexico	248	445	540
New Jersey	500	603	625
North Carolina	252	392	
Pennsylvania	1500	1965	2146
Vermont	75	63	250*
Virginia	675	990	1100

Note: Q=Quarter. Empty cells represent data not collected in a given quarter by a given state.

[1] Quarter 9. Data from quarter 8 was not available in this format.

Objective 3: *A method to identify local parent/family controlled organizations, to foster network activities among these local organizations, and to obtain information on activities of these organizations.*

TABLE 4. Number of active support groups in the state.

STATE:	Q1	Q5	Q9
Georgia	9	13	12[1]
Hawaii	3	9	7[1]
Kansas	9	14	27
Mississippi	17	14	8
Montana	23	24	
Nebraska	5	8	7
New Mexico	1	0	5
North Carolina	8	12	4
Vermont	8	12	4
Virginia	24	28	21
Wisconsin	9	12	11

Note: Q=Quarter. Empty cells represent data not collected in a given quarter by a given state.

[1] Quarter 9. Data from quarter 8 was not available in this format.

Objective 4: *A system of referring family members to existing family groups or to individual family members in their geographic area and for directing parents to existing agencies with the ability to answer questions and make referrals within the service delivery system.*

TABLE 5. Referrals to support groups.

STATE:	Q1	Q5	Q8
Georgia	7	51	43
Hawaii	29	10	69
Kansas	8	16	
Mississippi	0	32	17[1]
Minnesota	104	90	209
Montana	31	40	14
Nebraska	27	40	21
New Mexico	15	20	34
New Jersey	33	8	2
North Carolina	75	70	106[1]
Pennsylvania	25	50	50
Texas	8	33	9
Vermont	12	7	1
Virginia	8	10	12

Note: Q=Quarter.

[1] Data from quarter 9. Data from quarter 8 was not available in this format.

TABLE 6. Referrals to Family Members

STATE:	Q1	Q5	Q8
Georgia	14	89	70
Hawaii	2	11	69
Kansas	3	10	
Mississippi	0	13	9[1]
Minnesota	46	86	34
Montana	21	20	6
Nebraska	2	29	15
New Mexico	3	2	6
New Jersey	24	18	4
North Carolina	74	117	131[1]
Pennsylvania	25	45	48
Texas	4	29	7
Vermont	1	3	5
Virginia	3	7	4
Wisconsin[2]	22	11	12

Note: Q=Quarter. Empty cells represent data not collected in a given quarter by a given state.

[1] Data from quarter 9. Data from quarter 8 was not available in this format.

[2] Referrals to MUMs (parent-to-parent matching service).

TABLE 7. Referrals to service providers.

STATE:	Q1	Q5	Q9
Georgia[1]	--	199	58
Hawaii[1]	117	125	222[2]
Kansas	6	15	134[2]
Mississippi[1]	5	43	14
Minnesota	109	81	221
Montana	75	95	56[3]
Nebraska	21	415	73
New Mexico	24	8	9
New Jersey	13	3	5
North Carolina[1]	30	7	118[4]
Pennsylvania	30	235	212
Texas	20	34	8[2]
Vermont[1]	1	24	133
Virginia	23	29	20[2]
Wisconsin[1]	32	36	43

Note: Q=Quarter.

[1] Requests for information or referrals.

[2] Data from quarter 8. Data from quarter 9 was not available in this format.

[3] Objective restated to inform parents about programs, services, and providers.

[4] Two or more categories of providers were combined; therefore, the figures may include duplicates if one person referred to more than one provider.

Objective 6: *A clearly articulated approach to providing technical assistance and support to newly forming or ongoing parent support groups, including "state-of-the-art" information on services for emotional disorders in children and adolescents, and the range of community based service options required to meet their needs.*

TABLE 8. Number of support group meetings attended to provide assistance.

STATE:	Q1	Q5	Q8
Georgia	1	3	1
Hawaii	4	4	0
Kansas	3	3	5
Mississippi	0	7	5[1]
Montana	22	22	
Nebraska	3	5	3
New Mexico	3	4	3
North Carolina	14	8	17[1]
Pennsylvania[2]		14	9
Texas	2	3	3
Vermont	5	14	1
Virginia	6	4	2
Wisconsin	4	5	4

Note: Q=Quarter. Empty cells represent data not collected in a given quarter by a given state.

[1] Data from quarter 9. Data from quarter 8 was not available in this format

[2] Information was not available for all areas, all month; therefore, these figures reflect minimum counts.

Objective 7: *A system for ensuring timely provision of information on pending legislation, state planning processes, opportunity for providing public comment or public testimony at various administrative or legislative hearings relevant to improving services for children and adolescents with serious emotional disorders and their families.*

TABLE 9. Number of calls about legislative issues.

STATE:	Q1	Q5	Q9
Georgia	35	14	2[1]
Hawaii	20	--	1[1]
Kansas	5	0	30
Mississippi	0	1	12
Minnesota	51	43	29
Montana	84	58	
Nebraska	4	30	45
North Carolina	15+	57	8
Pennsylvania[2]		10	4
Virginia	6	3	14

[1] Uses of phone tree

[2] Information not available all months for all regions; therefore, these figures reflect minimum counts.

THE DRIVING FORCE:
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EVALUATION FORM

1. Who used the report? (Check all that apply)
   ☐ Parent ☐ Educator ☐ Child Welfare Worker
   ☐ Juvenile Justice Worker ☐ Mental Health Professional
   ☐ Other (Please specify) ______________________________

2. Please describe the purpose(s) for which you used the report:
   ____
   ____

3. Would you recommend use of the report to others? (Check one)
   ☐ Definitely ☐ Maybe ☐ Conditionally ☐ Under No Circumstances
   Comments: ______________________________

4. Overall, I thought the report was: (Check one)
   ☐ Excellent ☐ Average ☐ Poor
   Comments: ______________________________

5. Please offer suggestions for the improvement of subsequent editions of this report:
   ____
   ____
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We appreciate your comments and suggestions. Your feeback will assist us in our effort to provide relevant and helpful materials. Thank you.

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